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The Experiential Model of the Person-Centred Record:  
A Social Constructionist Grounded Theory

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The life book attachment, discussed on pages 143-144, has been omitted at the request of the author due to the personal nature of the content.

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Joanne Mihelcic

15 April 2016

# Abstract

The objective of this research was to explore the co-creation of person-centred records, to support memory, identity and personhood, with the person diagnosed with early stage dementia. This thesis describes the design of a second generation grounded theory methodology and applied archival research. With its postmodern, continuum and social constructionist influences second generation grounded theory sees a shift in how we understand the researcher's interaction with participants in a study. It highlights the way relationships between researcher, participant and research data are both inseparable and the product of their combined interactions. Hearing and knowing participant voices requires methods and techniques sensitive not only to researcher and participants' words, but also their inherent meaning and actions.

A unique repertoire of interview techniques was undertaken with participants, to understand their experiences of memory, identity and personhood, in the context of early stage dementia. The interview process facilitated co-creating vignettes of stories which were centred on the person and their perspectives of life. Reviewing the vignettes with the participants facilitated exploration of the stories and meaning captured in these records of self. The recorded stories and the processes for co-creating records of these stories were analysed using a social constructionist lens; to develop new theory and knowledge about the potential ways in which these records may support stories of self and personhood.

The main contribution of this research was the development of a social constructionist theory of the Experiential Model of the Person-Centred Record. This is an integrative theory which describes the person-centred records as a particular type of record informed by theories of personhood and person-centred practice. Other outcomes of this research include:

- Contribution to research methodology and applied archival research
  - Designing a second generation grounded theory and innovative methods and techniques suited to the needs of working with people and their data.
- Contribution to archival theory
  - Application of the social constructionist lens, drawn from psychology and social psychology, for the study of interpersonal and social processes.
- Contribution to practice
  - This research is significant to the archival discipline as it creates an exemplar of reflexive and ethical practice involved in working within new and emergent problem spaces.

# Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other institution and affirms that to the best of my knowledge, the thesis contains no material previously published or written by another person, except where due reference is made in the text of thesis.

- (i) The thesis comprises only my original words towards the PhD.
- (ii) The thesis does not exceed 100,000 words in length, exclusive of tables, maps, bibliographies, appendices and footnotes.

# Acknowledgements

Firstly, I would like to acknowledge that this research was kindly supported by an Alzheimer's Australia Research Postgraduate Scholarship. The support of Alzheimer's Australia gave me the courage to believe that this type of work was important and could contribute to better understanding the perspectives and needs of people with dementia.

Secondly I would like to thank my supervisors Sue McKemmish, Cheryle Moss and Joanne Evans. These three people have shared their extensive knowledge and progressed through this learning journey with me. Sue, Cheryle and Joanne have each brought unique disciplinary perspectives and experience which have both challenged me and affirmed as necessary. I would also like to thank JoAnne Bevilaqua who provided support as an external clinical supervisor while I was undertaking interviews with participants in this research.

I had always said that I would only contemplate doing a PhD, if I could find a research interest that I could be passionate about for the necessary number of years. Sue McKemmish encouraged me to take questions, which emerged from my grandmother's experience in aged care and dying, and translate them into PhD research and new knowledge which contributes to how we can make a difference in real life contexts.

This thesis is the product of engaging with inspiring people who participated in this research. I would like to give a special thanks to the participants and their families for their time, energy and genuine interest in the research.

Special gratitude and thanks to my husband Francesco who has supported and reassured me as I progressed through each phase of what has been a life changing process.

I have had many fellow travellers – too many to mention all by name. We have explored the range of human emotions with regard to joys and frustrations of completing a PhD. Special thanks to Rebecca, Eve, Misita, Leisa, Hue and Liz for your ongoing friendships.

I would like to acknowledge my colleagues in the both the Faculty of Information Technology at Monash University, and the Australian Association of Gerontology for lively conversations and encouragement.

This study in memory and identity has been underpinned by my own experiences of caring for and losing family and dear friends: My father Tony, rarely shared his own personal stories. Yet, I will forever be very conscious of how these experiences impacted on his past, and continued to influence his perceptions of self and the world till he passed away in January 2015. Losing my father meant losing connections to a past which has powerfully influenced my own identity. Maria Grazia was one of my first students when I began teaching English in Trieste, Italy and became a dear and devoted friend. I remember fondly our long philosophical conversations about life, people and politics.

My mother Domenica once said that she was glad I was born when I was, because it has meant that I could pursue my passion for learning in ways that were never accessible to her. I do not take this opportunity to learn and do research for granted. It is a privilege.





# 1 Introduction: Making Time for Memories of Me

## 1.1 Introduction

The research reported on in this thesis has proved to be both an occupation and a passion. On reflection I can see how the research process and the outcomes are the product of who I am as much as the people with whom I engaged throughout. I can also grasp just how much I have been changed by the processes of working with inspiring communities of people to find ways of contributing to the betterment of society – even if only in small ways.

This research explored the co-creation of records to support memory, identity and personhood, with people diagnosed with early stage dementia. The findings of this second generation grounded theory research, in-depth interviews and reflexive practice in co-creating records resulted in a grounded theory of the person-centred record. I propose the concept of the person-centred record as a process and practice which is informed by personhood as a philosophical approach to working with people and records.

I explain my personal and academic experience in light of the problem space within which this research is situated. I introduce the research questions then establish the design of this second generation grounded theory; a method suited to this applied archival research and an approach to co-creating person-centred records in the context of people living with dementia.<sup>1</sup> The conceptual framework of this research is outlined in relation to the person dementia and creating records. The overarching structure and contribution of the thesis is also identified.

This chapter introduces how the research originated, and its situated context. I present my interests in working with second generation grounded theory to develop an approach to creating person-centred records, as an archival method, in the context of people living with dementia. I introduce the research aim and questions. The contexts and concepts within this research are discussed in relation to dementia and the struggle of remembering and in relation to creating personal records. The structure and contribution of the thesis are also identified.

- Section 1.2: Is an explanation of how I came to undertake this research and how this personal experience influenced my approach to this research.

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<sup>1</sup> “Applied research is concerned, first and foremost, with the usefulness and application of knowledge. Its primary focus is on the production of knowledge that is practical and has immediate application to pressing problems of concern to society at large or to specific public or private research clients. It is research that is designed to engage with people, organizations, and interests and is aimed to inform human services, public policy, and other local, national, and international decision makers.” Applied research has been described as a “powerful tool with the potential to contribute to both the growth of science and the amelioration of pressing real-life problems.” For a more in-depth discussion which explicates the types and uses of applied research see the entry on applied research by A. E. Brodsky and E. A. Welsh, “Applied Research,” in *The SAGE Encyclopedia of Qualitative Research Methods*, ed. L. M. Given (Los Angeles, CA: SAGE Publications, 2008), 17.

- Section 1.3: My personal and professional experience is positioned in relation to this research.
- Section 1.4: The research aims and questions which guided this research are identified.
- Section 1.5: I provide an overview of the methodology and design of this research.
- Section 1.6: Core concepts within this research are discussed within the broader disciplinary and research contexts.
- Section 1.7: I outline my intent for this study and how this influenced the outcomes of this research.
- Section 1.8: The constraints of this research are explained.
- Section 1.9: The anticipated outcomes of this study are detailed, with respect to the research aims and questions.
- Section 1.10: Provides an overview of each chapter in this thesis.

## **1.2     *How I Came to This Research Problem Space***

My journey into this research began when my maternal grandmother, at the end stage of her life, was moved into a nursing home in 2009. I was shocked to see how ‘unhomely’ the facility really was. The nursing home was a residence but it did not do justice to my grandmother’s lived experience, her memories, her relationships, either in the past or present. The straight corridors created structured thoroughfares between rooms and rows of beds. The functional furniture and fittings served their purpose though they were stripped of most of the personal artefacts or triggers which reflect the identity of the person who inhabited the space – even if only temporarily.<sup>2</sup> It was these triggers that served as the only evidence of the person’s life, other than memory, stories, events and relationships. In the case of my grandmother, and for many others like her, the institutions they lived in did not adequately support evidence of them as individuals or in the community.

I could not come to terms with how impersonal the nursing home was. I had nursed for several years when I first moved into the workforce, so I was very familiar with institutional care spaces. It disturbed me to think that, in an age where technology is ubiquitous and influencing self-expression and communication in ways we could not previously imagine, my grandmother was in a room devoid of most things that reflected who she was. At a time in her life when my grandmother, and we as her family, were trying to make sense of life and death, her worldly belongings were reduced to what could fit into a small wardrobe and bedside table. Yet, she was ‘lucky’ in that her bed was positioned next to the door so there was an extra shelf and a wall to hang photos of family and friends.

My grandmother’s mother tongue was Italian and as her health deteriorated she would often respond to English in Italian and vice versa. There was evidence of cognitive difficulty with

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<sup>2</sup> Giddens describes hospitals as health care institutions as evolving historically from the prisons and asylums of old. They were places that housed the poor, and, as much as attempting to provide for their physical requirements these institutions also concealed the chronic needs of the community behind closed doors. A. Giddens, *Modernity and Self-Identity: Self and Society in the Late Modern Age* (Palo Alto, CA: Stanford University Press, 1991).

some confusion and memory loss. The problem though was not always in the translation but rather in my grandmother not being able to communicate the personal meaning associated with even routine events or activities. The constantly changing staff roster and the high needs of the residents meant that there was not much time for residential carers to really get to know the people who lived there. How could the staff address the personal needs of the people, for whom this place was home if they did not know them personally?

During my grandmother's palliation I was undertaking coursework in Archival Systems as part of a Master's degree. We were studying the evidential nature of records and archives and their ability to witness to our lives as individuals and as members of society. The convergence of the personal experience with my grandmother and engaging in archival discourse led me to ask, if the power of records is to bear witness to our lives<sup>3</sup> then:

- Can we as researchers contribute to witnessing and evidencing the lives of those who are disadvantaged for reasons such as ill health, ageing or dementia, which can manifest in difficulties communicating personal memories, identity and meaning, not only of the past but into the present?
- What is the nature of these records which bear witness to our lives and how are they evidence of who we are in the changing contexts in which we live?

For the person diagnosed with dementia remembering and forgetting become critical and more conscious activities in maintaining a coherent sense of self. Autobiographical and biographical stories and events are routinely documented for use as aids in managing personal knowledge of and for individuals in the contexts of aged care. Existing research and anecdotal evidence indicate that the use of this type of biographical information is good in theory but difficult in practice.<sup>4</sup> Many of these records are created as a way of mitigating the loss of memories or used as triggers for remembering for the person with dementia in relationship with their carers. When creating memory aids is undertaken during moderate or more advanced stages of disease progression, the person to whom the records pertain may have diminished direct involvement in the processes of creation, decision-making or management of these records.

The processes of decision-making and agency around the creation and use of biographical information create challenges for individuals, their families, health professionals and increasingly the archival profession. Supporting the person with dementia in recording their own memories and stories raises questions about the processes for representing the perspectives of the person for whom they are created. How can research processes be developed to co-create records that support an individual's memories, identity and meaning? How can co-creating records allow the person to communicate who they are and their wishes into a time when they may struggle to make explicit knowledge of themselves, past and present into the future?

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<sup>3</sup> S. McKemmish, "Evidence of Me. . .," *Archives and Manuscripts* 24, no. 1 (1996), <http://www.infotech.monash.edu.au/research/groups/rcrg/publications/recordscontinuum-smckp1.html>.

<sup>4</sup> J. McKeown et al., "The Use of Life Story Work with People with Dementia to Enhance Person-Centred Care," *International Journal of Older People Nursing* 5, no. 2 (June 2010): 148–58.

### 1.3 ***Positioning My Personal and Professional Knowledge***

I came to this problem space with diverse prior knowledge. My professional and academic experiences included nursing, a teaching degree in music and drama, graduate studies in media studies specialising in the documentary as a genre, information and knowledge management, and, most recently archival science. Years of nursing reinforced that working with people requires developing empathy through understanding the needs of the individual. I learned and believe that the person is always there and present even if there are occasions where it is difficult to know or interpret what a person is experiencing. I developed skills in the arts and media learning to capture and represent what is sometimes difficult to put into words. My experience with the documentary film as a genre helped me develop a critical understanding of how perspectives are constructed and represented; truths are multiple, they are subjective and reality is not always as it seems.

As an information and knowledge management professional and archival researcher, I was conscious of how personal knowledge is evidenced in our activities and the products we as humans create. These records in turn not only become evidence of our existence but of the world we construct. How could I, as a researcher, understand the human relationship to records as an activity and as part of what makes us whole?

This research is part of a personal and academic journey I began whilst undertaking a Graduate Diploma in Media Studies nearly 20 years ago. During that time I discovered a passion for the documentary as genre of cinema. It was the very early days of digital video. Film-makers were experimenting with this new and much more affordable technology to record not only the big issues of life but also the more personal stories. These documentaries were a way of representing perspectives and a powerful medium for making sense of memory, identity, and relationships.

Influenced by this new technology and the idea of documenting my family story, I visited my father's family home in Slovenia for the first time in December of 1997. My father was from a small village near Ljubljana set in an isolated valley. I went to meet his side of the family with the hope that I might better understand traumatic and tragic events which dramatically altered the direction of my father's life, that of his siblings and the extended family. My father was orphaned when he was just seven years old, during the Second World War when both his parents were executed in their family home. My grandmother was six months pregnant at the time.

My father left Slovenia after the war and was never to return. He made excuses for not going back to visit but my understanding, which was confirmed in one conversation with him, was that he was scared to go back. It was only when I visited the village myself that I could start to comprehend the power of memories that have imprisoned this side of my family, so much so, that even now the extended family still feel the weight and grief of events which occurred over 70 years ago.

I initiated this connection with family, place and, in some ways, time so that I could make sense of my own personal stories. What had been my father's stories were being transformed

through the course of my life into my own stories. In those first visits to Slovenia I was conscious of how people were trying to reconcile their memories through their stories, records of family and war, and relationships which were testimony to what had occurred. What fascinated me most was the seeming redaction of evidence regarding people and events. There were photo albums with photographs missing. I was told that there was one man in the village who had recorded the event and cause of my grandparents' death in his diary, but had sworn to take this testimony to his grave. There was nothing but rubble left of my family's home. It was 50 years after the end of the war that a memorial was built to mark the loss of those killed and for whom there is no known resting place.

This journey marks a longstanding interest in how identity is constructed and perceived. We as human beings are part of a continuum of life and relationships. We are intimately connected to the experiences of others as well as ourselves. Memory and identity are never discrete. They are woven through our lives and the lives of those around us. We inherit and learn beliefs, values and emotions without always knowing exactly where they originate. My father rarely spoke of the events of his youth. It was the absence of these stories which made his pain more palpable. I had to take the journey back to his home village where relatives were able to give me insight into those stories of the past so I could make sense of their effect on the present.

I lived in Italy (on the border with Slovenia) for three years during which time I visited family in Slovenia several times. Each visit was a time to connect with people and then make the pilgrimage to where my grandparents' home once stood. I would leave with more questions than I had answers and the unsettling feeling that I was leaving a part of me behind. These were profound experiences which changed the way I perceived myself yet they were not represented anywhere in my current context.

Acknowledging this personal and professional knowledge is both a disclosure and affirmation of how I am positioned in this research. I see and reflect on the world through all these influences. I have drawn on these varied experiences in both theory and practice to create innovative approaches to applied archival research. In real life contexts we are working with people as well as their records. It is intimate and personal; it is centred on personal meaning.

## **1.4    *Research Aims and Questions***

The aim of this study was to understand the nature of the personally meaningful records as a social construct within the context of the person with early stage dementia. I explored how I, as an archival researcher, could study the relationship that humans have with records and the memories therein. I aimed to develop new theory about how people experience records through their co-creation, in a real world context where memory is fragile and the records become evidence of a life and identity still being lived.

I wanted to understand and situate this research in the unique contexts and perspectives of the person with dementia with regard to what was important for them and how this impacted on records of memory, personal stories and meaning. The overarching aim of this research was

to construct a second generation grounded theory of co-creating person-centred records in the context of early stage dementia. Further, to explore how second generation grounded theorising contributes to archival theory and possible implications for practice. The aim of this research is addressed through answering the following four research questions:

Research Question 1: How do individuals perceive what is important in creating their own personal records in their current context of early stage dementia?

Research Question 2: How do people represent their own memories and stories in ways that support the integrity of their identity and memory?

Research Question 3: How is meaning supported and sustained in the process of co-creating records?

Research Question 4: How do we achieve a rich understanding of the ethical issues and processes involved in this kind of record co-creation?

## 1.5 *Research Design and Methodology*

The work in this thesis represents a new approach to applied archival research. This was a new area of applied research,<sup>5</sup> and as such an exploratory study design was warranted. The nature of the research problem and questions required a methodology appropriate to developing new theory grounded in the context being studied. For these reasons a second generation grounded theory approach to the research design was implemented. I drew on the work of second generation grounded theorists Charmaz and Clarke, who have adapted the principles of traditional grounded theory, with its systematic analysis of data, to new problem spaces.<sup>6</sup> These theorists have extended grounded theory research in ways which are sensitive to postmodern influences; concerned with multiple perspectives, complexity, plurality, a participatory epistemology and continuum thinking.

I adopted two bodies of theory which supported a postmodern paradigm for working with people as well as understanding the meaning of records.

- A social constructionist lens served to study how the participants and I jointly constructed knowledge and meaning through this research, and the co-creation of person-centred records. Social constructionism provided a critical lens to challenge

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<sup>5</sup> Applied researchers, according to Patton, “work on human and societal problems...The purpose of applied research is to contribute to knowledge that will help people understand the nature of a problem in order to intervene, thereby allowing human beings to more effectively control their environment...the source of questions is in the problems and concerns experienced by the people and articulated by policymakers...Applied interdisciplinary fields are especially problem oriented rather than discipline oriented...Applied qualitative researchers are able to bring their personal insights and experiences into any recommendations that may emerge because they get especially close the problem under study during the fieldwork.” M. Q. Patton, *Qualitative Research and Evaluation Methods*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2002), 217.

<sup>6</sup> K. Charmaz, *Constructing Grounded Theory*, 2nd ed. (London: SAGE Publications, 2014). Kindle Edition.; A. E. Clarke, “Situational Analysis,” accessed July 24, 2014, <http://clarkessituationalanalysis.blogspot.com.au/>.

taken-for-granted assumptions regarding how we understand the phenomena and concepts being studied.

- Also important to this research was developing practices underpinned by postmodern and social constructionist theories of personhood. These theories originate from within philosophy and psychology and focus on studying and understanding interpersonal processes. These theories supported a person-centred approach to research.

A postmodern participatory epistemology emphasised the need to implement methods and techniques for hearing the person's voice and listening to their perspectives. I prepared a toolkit of methods and techniques for reflexively working with people and their data, in ways that were inclusive and collaborative. The research was conducted with three participants diagnosed with early stage dementia, who were still living at home. I undertook eight in-depth interviews with each participant in order to understand their perspectives and situated contexts. Central to the research activities was the sharing of personal stories and creating vignettes of these stories. Over the eight-week interview period I constructed a collection of approximately 60 vignettes with each participant. The research process and person-centred vignettes were analysed and coded to develop new knowledge and theory regarding the human relationship to the record and the nature of records which support memory, identity and personhood. Analysis of the data led to the achievement of the research aim through the generation of a second generation grounded theory, which makes a new contribution to archival theory. The grounded theory is called the Experiential Model of the Person-Centred Record.

## **1.6 *Situating the Research Problem Space***

To situate the research problem space in the following section I introduce key activities I undertook to establish the research. In this section I share the core concepts that I adopted for the study. The section is presented in three sub-sections:

- Developing sensitivity to the needs of the people with dementia
- Advocating for participation in archival research
- A conceptual framework.

### **1.6.1 Developing sensitivity to the needs of the people with dementia**

Motivated by my personal and professional experiences, and in the context of the unit on Archival Systems, I conducted a preliminary literature review exploring the nature of dementia, memory, identity and the significance of personally meaningful belongings in the context of aged care.<sup>7</sup> I also attended leading conferences and forums in gerontology and dementia to update my knowledge on what was happening in practice as well as in research. It

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<sup>7</sup> This exploratory review drew on literature from health sciences, information technology, media arts, social sciences and archival science. The objective was to understand the broader context of the problem space; that is the context of the person with dementia and the human relationship between memory, identity and artefacts which have personal meaning.

became evident, even at this early stage of conceptualising the problem space, that further research would require a cross-disciplinary approach to understanding concepts and the human relationship to records as representations of self.

What struck me so profoundly throughout this preliminary investigation is that research in dementia generally falls into two key areas or priorities (clinical and care); that of diagnosis or cure, then, care and the carer. Within these priorities varied perspectives were reflected, particularly when it came to the lived experience, of the person with dementia. There was much focus on the difficulty experienced by the carers who saw their loved ones ‘disappear’.<sup>8</sup> The words that I heard often in regard to the person with dementia, and still haunt me are “he/she is not the same person, she is not my mother/he is not my father”. There was a prevailing belief that the person had disappeared due to the dementia.

The perspective of the person with dementia was just barely present in research forums. At conferences on dementia and even in the literature the voice of the person with dementia was poignant and incredibly powerful. The messages were clear regarding their need to contribute in research and advocating for their own needs and experience.<sup>9</sup> The need to hear and understand the person’s voice became a key driver in how this research was designed and a fundamental concern in studying records to support memory and identity.

Attending the conferences, talking with researchers, and reflecting on the needs of people with dementia led me to consider preliminary themes of memory, identity and records. Engagement with this range of stakeholders assisted with the development of cross-disciplinary thinking.<sup>10</sup>

### 1.6.2 Advocating for participation in archival research

In 2007 as part of “Pluralizing the Archival Paradigm Through Education Project”, Gilliland et al. identified key strategies for extending the scope and quality of archival research and paradigms to include cross-disciplinary research. The authors identified the challenges of addressing diverse archival and recordkeeping needs, particularly the requirements of marginalised communities. They charged archival professionals to advocate for the direct participation of these communities, in conjunction to promoting their unique representation in archival contexts. Rather than the single disciplinary approach, working with these communities called for the use of lenses, frameworks and methods from outside the archival discipline.<sup>11</sup>

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<sup>8</sup> M. Downs, “The Emergence of the Person in Dementia Research,” *Ageing and Society* 17 (1997): 597–607.

<sup>9</sup> H. Wilkinson, “Including People with Dementia in Research: Methods and Motivations,” in *The Perspectives of People With Dementia: Research Methods and Motivations*, ed. H. Wilkinson (London: Jessica Kingsley Publishers, 2002).

<sup>10</sup> P. Stock and R. J. F. Burton, “Defining Terms for Integrated (Multi-Inter-Trans-Disciplinary) Sustainability Research,” *Sustainability* 3, no. 8 (July 26, 2011): 1090–1113, doi:10.3390/su3081090.

<sup>11</sup> A. Gilliland et al., “Pluralizing the Archival Paradigm through Education: Critical Discussions around the Pacific Rim,” *Archives and Manuscripts* 35, no. 2 (2007): 10.



Considering the implications of a participatory paradigm and researching across disciplines is an important step in extending disciplinary knowledge. Stember explains that especially “when a subject needs context, other disciplines are indispensable, forcing boundary changes... the problems of the world are not organized according to academic disciplines.” A key challenge...for researchers working across disciplinary borders is to remain open to concepts and how they are defined within the context of the problem being studied.<sup>12</sup>

Assumptions regarding the meaning and use of terminology have been described as a significant obstacle to effective interdisciplinary research.<sup>13</sup> Defining concepts is even more problematic when the objective of the research is exploratory and it brings into focus diverse perspectives of seemingly similar terms and concepts. Within and across disciplinary discourses the same terminology may hold various and sometimes disparate meanings. This research is located within the disciplinary context of archival science. The development of the grounded theory of the Experiential Model of the Person-Centred Record is clearly a primary contribution within archival science. In this sense, the understanding of what is person-centred is contextualised through the grounded theory and positioned within the disciplinary language and discourses of archival theory and practice. However, the research and the grounded theory emerged from cross-disciplinary knowledge and concepts. Further, working with people with dementia required that as the researcher I develop particular sensibilities that were informed by archival thinking, personhood in dementia, and social constructionism. Working within new problem spaces for applied archival research involved traversing theories and practice in health and social sciences. Researching and working with the person with dementia highlights the need to identify concepts, methodologies and theory which are relevant to studying this applied research problem. In the end, for this research the focus of the personal record concentrated on a type of record namely, the person-centred record.

In undertaking cross-disciplinary research the words used to describe the phenomenon being studied become even more salient. The concepts of memory, identity, personhood and personal record were all intrinsic to the research problem in which I was trying to understand the record as a construct for supporting individual memory and identity for the person with early stage dementia. In the broader context of this study I explored these terms through diverse bodies of theory and in light of cumulative research findings. On reflection, I would now describe the process of creating new knowledge across disciplines as discovering fellow accomplices. Each discipline or theory imbued unique meanings to terminology, and importantly perspectival knowledge of theoretical concepts.

The exploratory nature of the research problem required a grounded theory approach in the context of the participants and their data. Second generation grounded theory, with its emphasis on exploring the situated context from the ground up and postmodern underpinnings provided a methodology appropriate to learning from the data, in the first

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<sup>12</sup> M. Stember, “Advancing the Social Sciences through the Interdisciplinary Enterprise,” *The Social Science Journal* 28, no. 1 (1991): 2, doi:10.1016/0362-3319(91)90040-B.

<sup>13</sup> A. F. Repko, *Interdisciplinary Research: Process and Theory* (Thousand Oaks, CA: SAGE Publications, 2008).

instance, rather than applying a predefined schema of definitions.<sup>14</sup> The desired outcome of this approach to cross-disciplinary research was to contribute new understandings of the person-centred record in the context of early stage dementia.

### 1.6.3 A conceptual framework

Investigating complex problem spaces challenges not only how cross-disciplinary research is conducted but also how relevant core concepts are defined within and across the boundaries of discipline and theory.<sup>15</sup> In recognition of this it was important to develop a conceptual framework for this research, which involved constructions of dementia and personhood, and linkage of these to personal records and the challenges of remembering.

The conceptual framework and key terms from which this body of research was initiated was a landscape which considers firstly the needs of the person with dementia and their situated context. The theoretical concepts of memory, identity, personhood and personal records, were human processes which required a methodology and theory appropriate to exploring the human relationship to records as applied research processes. Throughout this thesis I engaged with these discourses in order to understand relevant concepts and determine their contribution to new grounded theory. In the rest of this section I will describe the key concepts, their relationships to memory and identity, and their relevance to this research:

- Dementia and personhood
- Personal records and remembering.

There is much to be learned from studying the relationships between the person with dementia and the study of personal recordkeeping. They both give reference to concepts of memory, meaning and identity, yet in society they are also often contested in terms of the lived experience and the perspectives that are represented. This thesis is part of an ongoing discourse which explores personal recordkeeping as applied research and in the lives of those who author the content. The context itself is studied in relation to the records existent and co-created.

These conceptualisations, of personal recordkeeping and its relationship to memory, and identity in the context of dementia are explored in this research as part of a discourse. How self is represented through the creation of records is closely connected to theories of how remembering is mediated via the artefacts we create. van Dijck explains how “mediated memories means our memories are embodied by individual brains and minds, *enabled* by the technologies and material objects that render them manifest, and *embedded* in social practices and cultural forms”.<sup>16</sup> In considering all these dimensions it is understandable that for van

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<sup>14</sup> K. Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (London: SAGE Publications, 2006); A. E. Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn* (San Francisco, CA: SAGE Publications, 2005).

<sup>15</sup> G. W. Blackwell, “Multidisciplinary Team Research,” *Social Forces* 33, no. 1 (January 1, 1954): 367.

<sup>16</sup> J. van Dijck, “Mediated Memories as Amalgamations of Mind, Matter, and Culture,” in *The Body Within: Art, Medicine and Visualization*, ed. R. van de Vall and R. P. Zwijnenberg (Leiden: Brill, 2009), 172, <https://books.google.com.au/books?id=AtWwCQAAQBAJ>.

Dijk the complexity of memory requires a multidisciplinary approach; personal memory, “is a complex of physical-mental, material-technological, and sociocultural forces”.<sup>17</sup> Memory is situated in the way “(external) memory objects” interact with the mind to serve as representations and triggers of self through time and space and “as an index to lived experience”.<sup>18</sup>

Here concepts are phenomena and not the unique domain of any one discipline. Identity, for example, has been taken up broadly, both within sociology and psychology. Contemporary social theorists have extended the concept of identity to include social identity, which is defined by the extent to which individuals identify themselves in terms of group membership.<sup>19</sup> “Collective identities are seen as implying notions of group boundedness and homogeneity, and an emotional sense of belonging to a distinctive, bounded group, involving both a felt solidarity with fellow group members and a felt difference from outsiders.”<sup>20</sup> Perspectives of memory and identity are human activities; they are plural and in multiple disciplinary contexts.

Memory and emotions are fundamental to remembering and knowing who we are in the world. Social scientist Mitzal synthesised multiple texts to describe the importance of remembering. She argues that it is “fundamental to our ability to conceive the world”, “it is the most important element in the account of what it is to be a person”, and “it is the central medium through which identities are constituted”. Further, remembering “is the guardian of difference”, Mitzal explains this as core to accumulating self “through our unique lives”, by facilitating the “recollection and preservation of our different selves”.<sup>21</sup>

Temporality is the thread that draws our existence from one event to the next. It is these “past events which influence the present...and are explicitly reconstructed by the person who experienced them as episodic memory. If remembered, [it] becomes an example of autobiographical memory and may form part of a life narrative. Life narratives are significant because they are one way of defining the self.”<sup>22</sup> Life narratives are much more than an account of events. They are activities and processes for sense making. So, what happens when these activities are communicated and recorded? What is the significance of the recorded narrative? What is the meaning of the products created?

Evolving paradigms of personhood emphasise the importance of supporting an individual’s identity through biographical knowledge of the person.<sup>23</sup> The recording of autobiographical knowledge has received recognition as a useful and powerful tool for communicating an

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<sup>17</sup> Ibid., 165.

<sup>18</sup> Ibid., 166.

<sup>19</sup> K. A. Cerulo, “Identity Construction: New Issues, New Directions,” *Annual Review of Sociology* 23 (January 1, 1997): 385–409, doi:10.2307/2952557.

<sup>20</sup> B. A. Mitzal, *Theories of Social Remembering* (Maidenhead: McGraw-Hill Education, 2003), 133.

<sup>21</sup> Ibid., 1.

<sup>22</sup> U. Neisser, “Self-Narratives: True and False,” in *The Remembering Self: Construction and Accuracy in the Self-Narrative*, ed. U. Neisser and R. Fivush (Cambridge: Cambridge University Press, 1994), 1.

<sup>23</sup> T. M. Kitwood, *Dementia Reconsidered: The Person Comes First*, Rethinking Ageing Series (Buckingham: Open University Press, 1997).

individual's life story and personal meaning in the context of health care. Though there are a range of methodologies used to capture and remind people of their stories and identity, it is life story work as a technique which involves explicitly "recording relevant aspects of a person's past and present lives in some way, and then using this life story to benefit them in their present situation."<sup>24</sup> The recording of biographical and autobiographical information in life story work serves the specific purpose of supporting individual memory and identity. The techniques and products of life story work are also used to help understand personhood, and in doing so, influence care which respects the unique experiences of the individual. Due to the cognitive impact of dementia, when the practice of recording personal knowledge is predominantly undertaken, the activities are facilitated by family or care staff. These are practices for co-creating records which represent life stories and autobiographical information.

In 2004, McKeown, Clarke and Repper conducted the first systematic literature review of life story work as documented in the disciplines of health care and social care practice. They identified many different approaches which reflected life story work but no singular definition. They drew on earlier work that came out of the Centre for Policy on Ageing in London and created this guiding definition of life story work for their review process.<sup>25</sup>

Life story work is a form of intervention carried out in health or social care practice, and is an umbrella term, encompassing a range of terms/interventions, for example biography, life history, life stories. It is usually undertaken to elicit an account of some aspect of a person's life or personal history that goes beyond a routine health assessment undertaken to plan care and treatment, and aims to have an impact on the care the person receives. Life story work implies collaboration with another/others to gather and record information, and it usually results in a 'product', for example a story-book, collage, notice board, life history/biography summary, or tape recording. It is an ongoing, dynamic process rather than a task to be completed and is usually planned and purposeful, although it does not need to be carried out systematically.<sup>26</sup>

This eclectic definition highlights the range of purposeful activities in life story work, as a continuum of relationships and processes. Personal storytelling is performed, constructed and recorded. The intent of these practices is to facilitate reciprocal relationships between those who participate in the storytelling events. While the perceived benefit of this activity was positively reported "evidence on the use of life story work is immature." McKeown, Clarke and Repper acknowledged the need for further research into the use of life story work, particularly, as it was difficult to determine how well the terminology used adequately reflected the techniques implemented.<sup>27</sup>

The practice of creating memory aids, in the contexts of aged care and disability, raises many concerns regarding the processes for creating purposeful and meaningful records of self.

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<sup>24</sup> J. McKeown, A. Clarke, and J. Repper, "Life Story Work in Health and Social Care: Systematic Literature Review," *Journal of Advanced Nursing* 55, no. 2 (2006): 238, doi:10.1111/j.1365-2648.2006.03897.x.

<sup>25</sup> Ibid.

<sup>26</sup> Ibid., 238–239.

<sup>27</sup> Ibid., 237.

The term personhood and its evolving definitions are fundamental to the values and beliefs which I bring to applied research. Supporting people in terms of their memories and identity required a sensitive and inclusive approach which understands their needs from their perspective. It is about their memories and the stories they want or need to tell and how they are communicated through time and space.

In this section I have shared how I worked with developing sensitivity to the situated context of the person with dementia and the place of the person-centred record within archival theory and practice. Further, I have identified the importance of remembering as a human activity and its relevance to the creation of person-centred records.

## **1.7 *Researcher Intent and Goals for the Research***

I undertook this study with the aim of contributing new knowledge about the nature and purpose of personal records as a means of communicating and representing the self in archival science and the community of stakeholders for whom dementia is a part of their lived experience.

I used the context of the person with early stage dementia to direct me to the concepts and theories, used within health sciences which are most closely associated with caring for and understanding the perspectives of people with dementia. I drew on the theories and literature of archival science which are concerned with the remembering and personal recordkeeping and considered the broader impact and meaning of records for individuals and society. The thinking is influenced profoundly by philosophical and sociological theories referred to in those traditions.

I explored and brought together existing knowledge across the disciplines which supported new applied approaches to research in archival theory. In the same vein I sought to understand how developing processes for archival practice could contribute to knowing a person. The findings of this personal knowledge could contribute to the discourse on what it means to be person-centred. There is limited research representing the perspectives of the person with dementia as the principal stakeholder. As such, it was my intention to develop the research processes so they could be adapted for and centred on the person with dementia.

In order for this research experience to be person-centred I worked to:

- Situate and make sense of the varied and sometimes contested perspectives of the person with dementia and personal records, by engaging with the broad community of stakeholders; the person with dementia, family, practitioner and academic.
- Design research processes which are sensitive and flexible; a person-centred approach to working with people and exploring personal records.
- Develop collaborative and reflexive interview processes to understand what is important for the participants in this research – their unique perceptions of self and the world.
- Explore how a person's unique perspectives and identity may be represented through co-creating personal records in their situated context.

- Explore the construction and meaning of recording personal knowledge and personal records.
- Provide new insight regarding the lived experience of dementia and the human relationship with personal recordkeeping.

## **1.8 Constraints of Design Created Opportunities for this Research**

The constraints in this project were also opportunities for doing in-depth work with participants. The second generation grounded theory approach to this research required the collection of in-depth data over several months. The data revealed complexity in the situated contexts of personal recordkeeping and people living with dementia. Constant comparative analysis of such rich and expansive data required many layers of analysis and theorising. Data collected will always be only a small representation of a person's whole life while set in a particular time and place.

Below I list key considerations for designing this research and working with participants.

1. Working with people:
  - I chose to work with a small number of people, so the participants and I could do very in-depth work.
  - Interviewing three people over an extended period of time allowed me to get to know the participant and their family and vice-versa.
  - Interviewing participants in their own home required considering my physical and psychological needs as well as that of the participants. It was necessary to assess and manage the risks. This personal context facilitated exploring the person's perspectives with regard to their memories, stories and acts of recordkeeping.
  - The participant's physical and cognitive needs enhanced my need to be sensitive and attuned to the person and how the research was conducted.
  - Sharing personal stories through the lived experience of dementia meant that participants sometimes revealed their deepest thoughts and experiences. It can be emotional and taxing for the researcher and the participant.
  - Recruiting the person with dementia, even at an early stage, was difficult. The context with regard to family and health required flexibility on my behalf and interviews were rescheduled when necessary.
2. Methodology and studying personal recordkeeping:
  - I was challenged to design a second generation grounded theory which would allow me to work with complexity and plurality in this specific context.
  - Using second generation grounded theory as methodology meant that the study was exploratory and the findings were cumulative. Personal records were being explored and defined in this particular context.

- The research was not designed nor undertaken as a clinical study though the findings are perceived to have therapeutic relevance.
3. Recruiting participants:
- Carers were dealing with conflicting demands regarding family and health.
  - Participant availability depended very much on the carer's perception of the research and their ability to accommodate the research interviews.
  - The participants were referred to me, as the researcher, by family, carers or health care workers who in these circumstances were the gatekeepers. As such, the process of communicating the project and the initial informed consent required an extra face-to-face meeting with the participant to ensure that they understood the project, their involvement and the process.

In this research I was working with people with early stage dementia and records. As such, it was a complex human context which required working within the constraints and opportunities of participant worlds, as well as the research.

## **1.9     *Outline of Anticipated Outcomes and their Significance***

The aims and outcomes of this research reflect a second generation grounded theory approach for studying the phenomenon of personal recordkeeping. The outcomes are the product of flexible techniques for working with participants and data which is consultative and grounded with the people being interviewed. In Table 1 I have identified the key outcomes of this research in relation to the research questions.

**Table 1 Research aims and questions with outcomes**

Research aim and questions	Outcomes
The overarching aim was to construct a second generation grounded theory of co-creating person-centred records in the context of early stage dementia. Further, to explore how second generation grounded theorising contributes to archival theory and possible implications for practice.	<ul style="list-style-type: none"> <li>• A grounded theory and model which highlight important theoretical dimensions in understanding the human relationship to person-centred records.</li> <li>• Theory building which extends knowledge and concepts relating to the person-centred record in theory, through practice and the act of co-creating person-centred records.</li> </ul>
1. How do individuals perceive what is important in creating their own personal records in their current context of early stage dementia?	<ul style="list-style-type: none"> <li>• Rich understandings of the ‘things’ that are important and meaningful from the perspective and understanding of the person in the context of early stage dementia.</li> <li>• An exemplar of the types of personal stories, memories, objects and relationships which are important to the three individuals with early stage dementia and why they are meaningful.</li> </ul>
2. How do people represent their own memories and stories in ways that support the integrity of their identity and memory?	<ul style="list-style-type: none"> <li>• A responsive approach to research design through methodologies and techniques which are sensitive to participants’ perspectives and choices they make.</li> <li>• Techniques for co-creating records which represent personal stories, memories and identity in relationship to the person with dementia.</li> </ul>
3. How is meaning supported and sustained in the process of co-creating records?	<ul style="list-style-type: none"> <li>• Implementation of a social constructionist lens in order to examine how meaning and records were co-constructed.</li> </ul>
4. How do we achieve a rich understanding of the ethical issues and processes involved in this kind of record co-creation?	<ul style="list-style-type: none"> <li>• An exemplar of applied archival research and in-depth study of co-creating records in the real world context of the person with dementia.</li> </ul>

## 1.10 Thesis Overview

### Chapter 2 Backgrounding theory and sensitising concepts

In Chapter 2 I expand on the core concepts introduced in Chapter 1 through a theoretical discussion of what is described in grounded theory research as sensitising concepts. I present the relevant literature related to researching with people who have dementia and to investigating personal stories, using storytelling to support memories, and to create person-centred records with people. Core concepts for the thesis are developed through an exploration of the key theoretical and conceptual sources related to the postmodernism, a participatory epistemology, records continuum thinking, and the purpose and meaning of personal records in archival work.

### Chapter 3 Research methodology: In theory and in practice

In Chapter 3 I explain the rationale for using second generation grounded theory as the research methodology for this study. The underlying methodological principles of this



approach are identified and summarised. The fit of this methodological approach, with its inherent social constructionist lens, is argued in relation to the principles of records continuum thinking, and as a sound basis for the developing the person-centred record in the context of people with dementia. I present the design of the research and the methods and techniques implemented in the course of this study. In this chapter I present the processes for recruiting participants, the methods of data collection and data analysis, and the ethical considerations required for clearance of this project. In the remainder of the chapter I present a summative and explanatory account of how the research processes were enacted and progressed throughout the study.

#### **Chapter 4 Findings 1: Innovation in working with people and their data**

Chapter 4 is the first of three chapters in which the results of the grounded theory study are presented. In this chapter I introduce the participants in this research. The first findings are presented in relation to co-creating vignettes as person-centred records for each of the participants in the study. Particular attention is paid to revealing the processes of sharing stories and co-creating records. I report on the ways in which the participants' personal and situated contexts were engaged with and understood during this archival research and grounded theorising processes. This is followed by an account of the research processes that were used to co-create vignettes and life books as personal records with the participants.

#### **Chapter 5 Findings 2: Analysing shared memory-making and co-creating the person-centred record**

Chapter 5 is the second of three chapters in which the results of the grounded theory study are presented. In this chapter I present the findings related to the overarching themes, interrelated ground theory coding and the research processes involved in co-creating the vignettes of personal stories in the study. I share the findings from the coding activities which resulted in identification of the core code of the person-centred record. I describe the categories of meaning which emerged from analysis of person-centred records. Together these codes and categories reveal salient aspects of the records present in shared memory-making and co-creating personal records. The grounded theory strategies of mapping and selective coding were built on these open coding findings. The selective coding resulted in findings related to key conceptual aspects of the person-centred record.

#### **Chapter 6 Findings 3: A social constructionist grounded theory of the person-centred record**

Chapter 6 is the third of three in which the results of the grounded theory study are presented. In this chapter I present findings related to generating a social constructionist grounded theory of the Experiential Model of the Personal Record. The findings presented in this chapter were built from further theorising of the results presented in Chapters 4 and 5. The relationship between personhood and co-creating the person-centred records with people who have dementia is revisited and an experiential model of the personal record is presented. This model is explained in relation to the concepts which emerged in the selective coding process.

## **Chapter 7 Discussion: A social constructionist grounded theory of the person-centred record**

Chapter 7 is a discussion of findings from this study in which I return to the overarching aims and research questions. The discussion is focused through three key areas: the social constructionist theory of the Experiential Model of the Person-Centred Record generated in this research; evaluating the construction of this second generation grounded theory; and ethics and reflexivity in the process of co-creating the person-record and the experiential model of the record.

## **Chapter 8: Conclusion: Developing theory and practice for co-creating person-centred records**

The thesis is concluded in this chapter. A summation of the research, key contributions, and implications is stated along with a summary of outcomes and their significance.

Recommendations arising from this research are listed. The chapter concludes with a vision for how the findings of this research could potentially be developed into new ways of working with people and technology.

### **1.11 Conclusion**

In this chapter I introduced and situated this research project. I explained my interests in working with second generation grounded theory to develop an approach to creating person-centred personal records, as a method suited to archival research, in the context of people living with dementia. I put forward the research aims and questions, and established the context and conceptual framework of the research inquiry in relation to dementia and the struggle of remembering and in relation to creating personal records. The structure and contribution of the thesis was also identified.

Developing new knowledge is a gift received and a gift to share. There were many types of knowledge created through this project. I would like to emphasise that I have learned much through the lives of the people who participated in the research process. As a new researcher I remember how I was filled with fear as I began interviewing participants. As researchers we report on the processes we undertake in conducting a study but the participants in this study were incredibly wise. I understand this because I have known them personally. I have heard their stories and studied their words with attention and detail. These people shared altruistic reasons for being involved in this study but they enriched my own life as well as having contributed to the research.

## 2 Backgrounding Theory and Sensitising Concepts

### 2.1 Introduction

The aim of this second generation grounded theory study was to explore the co-creation of person-centred records which support memory, identity and personhood in the context of the person diagnosed with early stage dementia. In Chapter 1 I introduced the research aim and questions and key ideas which underpinned the research problem. This thesis creates new ground for applied archival research. As such it is drawing on knowledge from outside the discipline to extend understandings of contexts, theories and practice. The challenge with all these sensitising concepts lies in that they are adopted, imagined and theorised through various disciplinary paradigms and theoretical lenses.

In congruence with second generation grounded theory as a methodology described in the literature, this chapter presents the background theory and sensitising concepts in order to frame the research and position knowledge which informs existing concepts. This chapter is a “‘contextualisation’ of the study, rather than a traditional literature review.”<sup>28</sup>

The objective of constructing this chapter is twofold:

- To understand postmodern paradigms and theories and their influence on knowledge of and researching with people diagnosed with dementia.
- To explore the theoretical paradigms and sensitising concepts with particular reference to postmodern influences in archival science and understanding the record as a personal construct and co-creation.

This chapter is structured in order to demonstrate the reasoning through which the theory and concepts are framed.

- Section 2.2: Developing theoretical sensitivity is explained as an important part of grounded theory research and practice and in order to position this chapter of the thesis.
- Section 2.3: Paradigms and postmodernism are explored as overarching influences which inform disciplinary communities, their understanding of concepts and development of theory. In this section I introduce records continuum thinking, as a postmodern archival paradigm from the perspectives of archival theorists who have discussed postmodern influences on the ways recordkeeping is being engaged and understood.

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<sup>28</sup> It is established practice within grounded theory research that only the theories and concepts directly related to the findings and theorising are pulled through in the final discussion. C. Dunne, “The Place of the Literature Review in Grounded Theory Research,” *International Journal of Social Research Methodology* 14, no. 2 (August 31, 2010): 121, doi:10.1080/13645579.2010.494930.

- Section 2.4: Records are discussed in relation to how they are perceived in supporting meaning, memory and identity. This research is positioned within the evolution of a participatory epistemology emerging through postmodernism and its influence within the broader academy, research methodologies and archival science.
- Section 2.5: Perceptions of the person with dementia are explored within the broader situated contexts with a particular focus on postmodern influences and theories of personhood.
- Section 2.6: I situate this thesis within emergent archival research and literature of which this research is a part.

## **2.2     *Developing Theoretical Sensitivity, Sensitising Concepts and a Theoretical Framework in Grounded Theory***

The concepts and theories reported in this chapter were an important part of contextualising this second generation grounded theory, and part of the ongoing development of theoretical sensitivity through data collection and analysis as well as the theorising stages of this thesis.<sup>29</sup> Developing theoretical sensitivity is a process described in grounded theory research, of incorporating the researcher's personal and intellectual history, and insight as knowledge into their ways of thinking.<sup>30</sup> This chapter positions and extends this investigation into the broader research context of the person with dementia as well as the archival discipline and literature from which this research emerges.

Urquhart emphasises that in grounded theory research the “literature review should be non-committal and the emerging theory will determine the relevance of the literature”.<sup>31</sup> The grounded theory researcher does not “impose existing theories or knowledge on the study processes and outcomes” and they must remain open to the data and findings; purposefully reading “outside of the topic area to avoid contaminating and constraining the analysis of data with extant codes and concepts”.<sup>32</sup> This challenge to remain open to the data is enhanced by the recognition that researchers are not a blank slate with their expertise built on a range of prior knowledge and experience.<sup>33</sup>

In addressing the challenge to remain open to data, grounded theorists have developed particular approaches to how they work with existing concepts and theories. As Charmaz explains, sensitising concepts and theoretical frameworks, in grounded theory research, are the products of analysing and constructing the argument. Sensitising concepts and theories inform and influence the worldview of the researcher, though these same concepts and

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<sup>29</sup> Dunne, “The Place of the Literature Review in Grounded Theory Research.”

<sup>30</sup> M. Birks and J. Mills, *Grounded Theory: A Practical Guide*, 2nd ed. (London: SAGE Publications, 2015), 12. Kindle Edition.

<sup>31</sup> C. Urquhart, *Grounded Theory for Qualitative Research: A Practical Guide* (Los Angeles, CA: SAGE Publications, 2013), 193.

<sup>32</sup> D. Birks et al., “Grounded Theory Method in Information Systems Research: Its Nature, Diversity and Opportunities,” *European Journal of Information Systems* 22, no. 1 (2013): 22.

<sup>33</sup> Urquhart, *Grounded Theory for Qualitative Research: A Practical Guide*, 193.

theories “remain in the background until they become relevant for immediate analytical problems.”<sup>34</sup>

Further, Charmaz make three important points regarding the need for researchers to sensitise themselves to concepts as they engage in grounded theory. She says:

Sensitizing concepts offer ways of seeing, organizing, and understanding experience; they are embedded in our disciplinary emphases and perspectival proclivities. Although sensitizing concepts may deepen perceptions they provide starting points for building analysis, not ending points for evading it. We may use sensitizing concepts only as points of departure from which to study the data.<sup>35</sup>

The term sensitising concept was coined by Blumer and has been adopted within grounded theory to describe the ways existing concepts are used within grounded theory research.<sup>36</sup> Sensitising concepts and disciplinary perspectives create a “loose frame” from which to begin the collection and analysis of data.

A sensitizing concept is a broad term without definitive characteristics; it sparks your thinking about a topic (Hoonard, 1996). Sensitizing concepts give researchers initial but tentative ideas to pursue and questions to raise about their topics. Grounded theorists use sensitizing concepts as tentative tools for developing their ideas about processes that they define in their data. If particular sensitizing concepts prove to be irrelevant, then we dispense with them.<sup>37</sup>

My perspectives, through the diverse disciplinary experience, also informed the intentions for this research.<sup>38</sup> These perspectives were not fixed, but rather my understandings of concepts were influenced by an ongoing need to make sense of social reality and knowledge within the research. I have studied contexts and concepts in ways which were not bound to a single worldview, discipline or community of expertise. I was looking to understand how diverse disciplines and knowledge contributed to understanding this situated context, not only in theory, but with regard to the implications for applied archival research with the person with dementia.

An extensive review of the archival literature and engagement with archival communities revealed that the context and key concepts within this study, of co-creating person-centred records with people diagnosed with dementia, had not been reported (see Table 3 in Chapter 3, Section 3.4.4 for a comprehensive list of sources). Related terms such as personal record, memory and identity were discussed in the archival literature, but within very different

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<sup>34</sup> Charmaz, *Constructing Grounded Theory*, 311.

<sup>35</sup> K. Charmaz, “Grounded Theory: Objectivist and Constructivist Methods,” in *Strategies for Qualitative Inquiry*, ed. N. K. Denzin and Y. S. Lincoln, 2nd ed. (Thousand Oaks, CA: SAGE Publications, 2003), 259.

<sup>36</sup> Charmaz, *Constructing Grounded Theory*; G. A. Bowen, “Grounded Theory and Sensitizing Concepts,” *International Journal of Qualitative Methods* 5, no. 3 (September 1, 2006): 12–23, doi:10.1177/160940690600500304.

<sup>37</sup> Charmaz, *Constructing Grounded Theory*, 30.

<sup>38</sup> V. Gillies and P. Aldred, “The Ethics of Intention: Research as a Political Tool,” in *Ethics in Qualitative Research*, ed. M. Mauthner, M. Birch, and T. Miller, SAGE Research Methods (London: SAGE Publications, 2002), 1.

contexts and not situated in this type of applied research. The focus of the literature was on the role of existing records and archives in the lives of individuals and communities, rather than the co-creation of records to support memory and identity. Understanding the co-creation of person-centred records with people with dementia introduced the criteria of addressing the needs of individual people as well as concerns with the records being created. Relevant expertise was situated in diverse bodies of literature and across a range of disciplines.

In this section I have explained the role of theoretical sensitivity in grounded theory and its purpose in this chapter. The following sections report on how I developed sensitisation in this research and the concepts explored by backgrounding the theory.

## **2.3 Postmodern Approaches to Archival Thinking and Records**

In this section I summarise some key theoretical archival perspectives which inform how this research was positioned and designed. The four areas covered in this section are:

- Paradigms and postmodernism: An overview
- Records continuum thinking: A postmodern paradigm for working with complexity
- Rethinking records: Structuration theory
- Postmodern archival paradigms: records, memory, meaning and identity

### **2.3.1 Paradigms and postmodernism: An overview**

This research is located within postmodern paradigms. In this section I briefly reference these terms and positions. The application and the relevance of postmodernism to archival thinking and records are discussed subsequent to this section.

Understanding the world around us requires comprehending the worldviews of those who inhabit these spaces. Disciplines and disciplinary knowledge are the products of communities, for whom the world is perceived in particular ways.

A paradigm may be viewed as a set of basic beliefs (or metaphysics) that deals with ultimates or first principles. It represents a worldview that defines, for its holder, the nature of the “world”, the individual’s place in it, and the range of possible relationships to that world and its parts, as, for example, cosmologies and theologies do.<sup>39</sup>

Guba and Lincoln were reminded by Stake, while writing the work cited above, that paradigms are themselves composed of “worlds within worlds, unending, each with its own paradigms. Infinitesimals have their own cosmologies.”<sup>40</sup> Paradigms do not live in isolation; they are part of a continuum of ways in which the world may be known. If the paradigm is both

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<sup>39</sup> E. G. Guba and Y. S. Lincoln, “Competing Paradigms in Qualitative Research,” in *Handbook of Qualitative Research*, ed. N. K. Denzin and Y. S. Lincoln (Thousand Oaks, CA: SAGE Publications, 1994), 107, <http://books.google.com.au/books?id=u8hpAAAAMAAJ>.

<sup>40</sup> Robert Stake as cited via personal communication in *Ibid.*, 116–117.

representative and a product *of* the community in which it is held, then as a paradigm shifts in relation to new challenges, so too are the holders of that paradigm also changed.

It is interesting to note that Kuhn did not have one single definition of paradigm.<sup>41</sup> Kuhn's writings showed an evolution of the many different meanings for the term paradigm; this in itself reflects the way defining terms and concepts is dependent on changing worldviews. The boundaries of meaning will always be influenced by context and perceptions, values and beliefs. It is as important to understand the historical as it is to acknowledge the possibilities. Paradigms in and of themselves serve to clarify the nature of what we know and believe within a certain context.<sup>42</sup>

Paradigms as worldviews are changed in the context of scientific inquiry and consequently change the world in which they exist. This is a reflexive process according to Kuhn. The world of scientific inquiry changes in response to arising anomalies and problem solving. We live in a world of ongoing investigation where the present is continuously evolving into new perceptions and knowledge. Paradigms are also a representation of the community's inherent relationship to that paradigm.<sup>43</sup>

There is debate across academia, professional schools and other sites of knowledge production, about just where we are in the context of the postmodern turn.<sup>44</sup> "Modernity is always contested and...constantly contesting older positions and creating new ones."<sup>45</sup> The postmodern theorist prefers to "abandon overarching paradigms and theoretical methodological metasystems" in order to position themselves within complexity by studying in detail the smaller, even fragmented parcels of knowledge in order to learn about the "the multiple levels of social reality".<sup>46</sup>

Postmodernism was the overarching paradigmatic influence which has informed archival communities through which the sensitising concepts and theoretical framework for this research were constructed. "Postmodernism...has many and various forms." Postmodernism is characterised by a belief in the uncertainty of global realities.<sup>47</sup> It is "the culture, including

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<sup>41</sup> Kuhn's *The Structure of Scientific Revolutions* published in 1962 was described by Gergen as "the single most influential constructionist volume of the [20<sup>th</sup>] century...As Kuhn proposed, our propositions about the world are embedded within paradigms, roughly a network of interrelated commitments to a particular theory, conception of a subject matter, and methodological practices." K. J. Gergen, *An Invitation to Social Construction* (London: SAGE Publications, 1999), 53.

<sup>42</sup> E. G. Guba, *The Paradigm Dialog* (Newbury Park, CA: SAGE Publications, 1990), 17–19.

<sup>43</sup> T. S. Kuhn, *The Structure of Scientific Revolutions: 50th Anniversary Edition*, (Chicago, IL: University of Chicago Press, 2012). Kindle Edition.

<sup>44</sup> A. E. Clarke, "Situational Analyses: Grounded Theory Mapping After the Postmodern Turn," *Symbolic Interaction* 26, no. 4 (November 2003): xxiv, doi:10.1525/si.2003.26.4.553.

<sup>45</sup> D. Kellner, "Zygmunt Bauman's Postmodern Turn," *Theory, Culture Society* 15, no. 1 (1998): 76.

<sup>46</sup> Borer, Silverman as cited in M. I. Borer and A. Fontana, "Postmodern Trends: Expanding the Horizons of Interviewing Practices and Epistemologies," in *The SAGE Handbook of Interview Research: The Complexity of the Craft*, ed. J. F. Gubrium et al., 2nd ed. (Thousand Oaks, CA: SAGE Publications, 2012), 45–60.

<sup>47</sup> C. C. Lemert, *Postmodernism Is Not What You Think: Why Globalization Threatens Modernity*, 2nd ed. (Boulder, CO: Paradigm Publishers, 2005), xiv, <https://books.google.com.au/books?id=FcVHAAAAIAAJ>.

the theories, of postmodernity; any culture or theory that studies, practices, celebrates, or otherwise takes seriously the breaking apart of modernity”.<sup>48</sup>

Within postmodern thinking, cross-disciplinary knowledge, language and terms are viewed as a way of highlighting differences while at the same time acknowledging cross-representation of meanings within and between concepts. This is often referred to as the crisis of representation. Describing what we know is epitomised in the concept of ‘crisis of representation’

[a] phrase coined by George Marcus and Michael Fischer to refer specifically to the uncertainty within the human sciences about adequate means of describing social reality. This crisis arises from the (noncontroversial) claim that no interpretive account can ever directly or completely capture lived experience. Broadly conceived, the crisis is part of a more general set of ideas across the human sciences that challenge long-standing beliefs about the role of encompassing, generalizing (theoretical, methodological, and political) frameworks that guide empirical research within a discipline. Symptoms of the crisis include the borrowing of ideas and methods across disciplines.<sup>49</sup>

Awareness of paradigmatic limits, postmodern positioning and the crisis of representation has informed the ways in which I have worked with archival concepts and theorising in relation to constructing the person-centred record. I as the researcher, as well as my research, sit within this continuum of ways in which the world may be known. These ways of knowing the world determine the position I took on how the research was conducted and interpreted, as well as the criteria for quality in inquiry. Working with uncertainty and how to deal with complexity is necessarily provocative. The research lens is focused on the world of the researcher as well as the research context. My interactions with people and society were reflective of societal norms and challenges as well as the disciplinary, personal and professional influences. “The ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific.”<sup>50</sup> In the same way that societal influences are plural so too were the perspectives that I as the researcher engaged with or held. As a postmodern researcher I was inquiring into the social context and I needed to be reflexive and sensitive to assumptions and practices in creating new knowledge.<sup>51</sup>

### **2.3.2 Records continuum thinking: A postmodern paradigm for working with complexity**

Within archival science, numerous paradigms which influence the encompassed communities, their worldviews, theoretical frameworks and practice are represented. Of particular concern to this thesis, which is positioned within the Australian archival community Records Continuum Research Group, are postmodern concepts of records and recordkeeping as the

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<sup>48</sup> C. C. Lemert, *Postmodernism Is Not What You Think* (Malden, MA: Blackwell, 1997), 67.

<sup>49</sup> T. A. Schwandt, *The SAGE Dictionary of Qualitative Inquiry* (Thousand Oaks, CA: SAGE Publications, 2007), 48.

<sup>50</sup> V. Burr, *Social Constructionism*, 2nd ed. (London: Routledge, 2004), Kindle Location 133. Kindle Edition.

<sup>51</sup> G. E. Marcus, “What Comes (Just) after ‘Post’? The Case of Ethnography,” in *Handbook of Qualitative Research*, ed. N. K. Denzin and Y. S. Lincoln (Thousand Oaks, CA: SAGE Publications, 1994).



activities associated with the creation, management and use of records. Postmodernist and continuum thinking have, within this community, been influential in reconceptualising the way records and archives are understood and theorised.

Describing records, their contexts and meaning requires understanding the concepts within archival paradigms; through the people, their worldview and their traditions. The complex nature of these concepts as social constructs raises further concerns regarding the theoretical assumptions. This research draws on records continuum thinking and practice, emanating from the Australian ‘recordkeeping community’ which signifies new approaches to recordkeeping and archiving education in Australia, along with collaborative research alliances.

These new postmodern and continuum based approaches are described as records continuum thinking; a framework which can be used to explore the complexities of recordkeeping environments by providing a multidimensional view of records in time and space. The postmodern influence, be it present or already past, “has not so much been the relativizing of truth (to the point even of making it irrelevant) but rather the multiplication of perspective”.<sup>52</sup> Upward explains that modelling complexity is different to modelling complication.<sup>53</sup>

The impact of postmodernisms and records continuum thinking in archives and recordkeeping, as described by McKemmish, Upward and Reed, acknowledges the many perspectives that influence the management of records. These perspectives include; “the personal and corporate recordkeeping activities undertaken by individuals in their everyday lives, in families, work or community groups and in organisations of all kinds”.<sup>54</sup> A continuum view of archives and recordkeeping recognises the layers of context and meaning that can be associated with a record and that its value is recorded in the iterative recordkeeping processes and rich archival description which allow it to be disembedded from it.<sup>55</sup>

In addition, Harris suggests that we should not consider all postmodern thinkers to be alike. Harris introduces the terms postmodernisms in the plural to signify the multiple perspectives which are constructed within the context of a broader intellectual heritage.<sup>56</sup> This positioning counters dualistic tendencies of seeing things as being one way or another. Cook further argues that archivists should adopt and be challenged by postmodernism as a paradigm and a way of thinking about the world. The discipline and their practice need to shift their focus to

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<sup>52</sup> Niek van Sas as cited in E. Ketelaar, “Tacit Narratives: The Meanings of Archives,” *Archival Science* 1, no. 2 (2001): 132.

<sup>53</sup> F. Upward, “Modelling the Continuum as Paradigm Shift in Recordkeeping and Archiving Processes, and beyond a Personal Reflection,” *Records Management Journal* 10, no. 3 (2000): 115–39.

<sup>54</sup> As explained in a personal communication with Frank Upward, his engagement with structuration theory came after the construction of the Records Continuum Model. S. McKemmish, F. H. Upward, and B. Reed, “Records Continuum Model,” in *Encyclopedia of Library and Information Sciences*, 3rd ed. (New York: Taylor & Francis, 2009), 4448, <http://www.tandfonline.com/doi/abs/10.1081/E-ELIS3-120043719>.

<sup>55</sup> S. McKemmish, “Placing Records Continuum Theory and Practice,” *Archival Science* 1, no. 4 (2001): 336.

<sup>56</sup> V. Harris, “Something Is Happening Here and You Don’t Know What It Is: Jacques Derrida Unplugged,” *Journal of Society of Archivists* 26, no. 1 (2007): 131–42.

“process rather than product, becoming rather than being, dynamic rather than static, context rather than text, reflecting time and place rather than universal absolutes”.<sup>57</sup>

It is the focus on processes of recordkeeping and archiving which denoted the context and relationship of records as logical objects.<sup>58</sup> At the same time records were being defined by their “evidential qualities, purposes and functionality.”<sup>59</sup> Understandings of records as evidence within archival paradigms, have as a consequence become closely tied to exploring the provenance, contextuality of the record creator and description of records and archives.<sup>60</sup> Australian archivists have been a prominent influence in exploring these concepts and addressing the postmodern challenge to consider the plurality of qualities, purposes and functions of records beyond a single immediate creator. This turn in thinking was shaped by postmodern paradigms, and underpinned by philosophical and sociological thinking, which emerged in the early mid 20<sup>th</sup> century.<sup>61</sup> Scott, in particular, was ahead of his time when during the mid-20<sup>th</sup> century he stated that “the physicality of the record has little importance compared to its multi-relational contexts of creation and contemporary use”.<sup>62</sup>

Considered in light of this research, records continuum thinking assisted my awareness of important postmodern work in relation to records. This included creating and working with records, not only in relation to archival paradigms but through people, their contexts and their personhood. Further, record continuum thinking supported understandings of complexities that needed to be experienced, lived and accounted for in co-creating person-centred records.

### 2.3.3 Rethinking records: Structuration theory

Further, work by Upward on structuration theory was useful in explaining aspects of records continuum thinking. In this section I describe relevant aspects of structuration theory.

Upward draws upon structuration theory to describe the continuum of action-based information processes reflected in the records continuum model.<sup>63</sup> (See Figure 1) Decision-making in the continuum “ceases to be about evaluating the value of a record for evidential and informational purposes from an archival perspective. Rather it becomes a multifaceted, recursive process which begins with defining what should be created (first dimension), what should be captured and managed as record (second dimension), what should be managed as a

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<sup>57</sup> T. Cook, “Archival Science and Postmodernism: New Formulations for Old Concepts,” *Archival Science* 1, no. 1 (2001): 3.

<sup>58</sup> McKemmish, Upward, and Reed, “Records Continuum Model,” 4447.

<sup>59</sup> *Ibid.*, 4447.

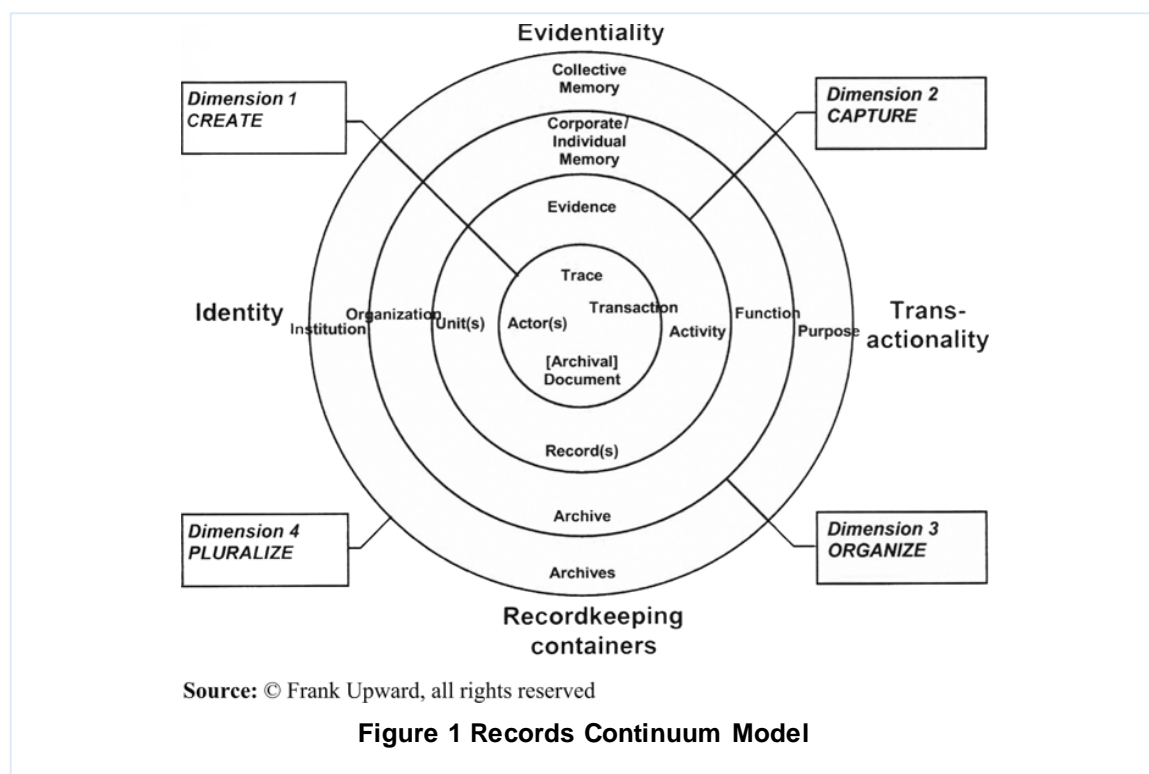
<sup>60</sup> T. Cook, “What Is Past Is Prologue: A History of Archival Ideas Since 1898, and the Future Paradigm Shift,” *Archivaria* 43, no. Spring (1997): 36.

<sup>61</sup> Borer and Fontana, “Postmodern Trends: Expanding the Horizons of Interviewing Practices and Epistemologies.”

<sup>62</sup> Cook, “What Is Past Is Prologue: A History of Archival Ideas Since 1898, and the Future Paradigm Shift,” 39.

<sup>63</sup> F. Upward, “The Records Continuum,” in *Archives: Recordkeeping in Society*, ed. S. McKemmish et al. (Wagga Wagga, NSW: Centre for Information Studies, Charles Sturt University, 2005), 197–222.

part of individual or organizational memory (third dimension) and what should be pluralized beyond organizational or individual memory (fourth dimension).”<sup>64</sup>



The ongoing evolution of records continuum thinking has been strongly influenced by Giddens’ work on the theory of structuration in which he explores the relationship between human agency and social structure. Structure in the context of social analysis refers to rules and resources “not of a patterning of presences but at the intersection of presence and absence; underlying codes have to be inferred from surface manifestations.”<sup>65</sup> It is distinguished by the separation of ‘system’ and ‘structure’ as well as the ‘duality of structure’ and has “time-space relations at the core of social theory”.<sup>66</sup> Structuration theory renders “the way societies are shaped by individuals and their memory traces, including the structures they set in place.”<sup>67</sup> Structuration theory focuses on the “conceptual investigation of the nature of human action, social institutions, and the interrelations between action and institutions”.<sup>68</sup>

An important concept in Giddens’ understanding of structure is represented in Figure 1, The Records Continuum Model.<sup>69</sup> In this model timespace distancing is where social systems

<sup>64</sup> McKemmish, Upward, and Reed, “Records Continuum Model,” 4455.

<sup>65</sup> A. Giddens, *Social Theory and Modern Sociology* (Palo Alto, CA: Stanford University Press, 1987), 18.

<sup>66</sup> C. G. A. Bryant and D. Jary, *Giddens’ Theory of Structuration: A Critical Appreciation* (London: Routledge, 1991), 13.

<sup>67</sup> A. Giddens, *Sociology*, 3rd ed. (Cambridge: Polity Press, 1997); A. Giddens, *The Constitution of Society: Outline of the Theory of Structuration* (Berkeley, CA: University of California Press, 1984) as discussed in Upward, “The Records Continuum,” 197.

<sup>68</sup> Bryant and Jary, *Giddens’ Theory of Structuration: A Critical Appreciation*, 201.

<sup>69</sup> Written permission has been received from Frank Upward to reproduce the model in this thesis. F. Upward, “Structuring the Records Continuum—Part One: Postcustodial Principles and Properties,” *Archives and Manuscripts* 24, no. 2 (1996): 268–85.

and social integration are not limited to physical connections but stretch across both time and space. These social interconnections are particularly significant when considering the nature of information processes and ‘remembering’ in technologically infused environments.<sup>70</sup> Structuration theory provides a lens for studying the social structure in relation to the person as agent.

Giddens’s reconstruction of social theory places an active person at the centre of sociological theory and modern society, who incorporates social structure into his/her very actions through reflexivity, or the “monitored character of the ongoing flow of social life”.<sup>71</sup> Modern social structures are only reproduced by reflexive individuals inhabiting an increasingly “detraditionalised” and globally interdependent world where old traditions and customs no longer provide signposts for how people should live, and who they should be.<sup>72</sup>

Structuration theory is meta level theory for the “conceptual investigation of the nature of human action, social institutions, and the interrelations between action and institutions”.<sup>73</sup> Structuration theory renders “the way societies are shaped by individuals and their memory traces, including the structures they set in place.” Duality of structure recognises both the agents and structures as being part of the same phenomena. In this sense structure is not a constraint and external to individuals but rather is part of a recursive process where memory traces are embodied in social practice of human agents and becomes part of the internal processes of the individual and society which can be reproduced across time and space.<sup>74</sup>

Structure...refers, in social analysis, to the structuring properties allowing the ‘binding’ of time-space in social systems, the properties which make it possible for discernibly similar social practices to exist across varying spans of time and space and which lend them ‘systemic’ form. To say that structure is a ‘virtual order’ of transformative relations means that social systems, as reproduced social practices, do not have ‘structures’ but rather exhibit ‘structural properties’ and that structure exists, as time-space presence, only in its instantiations in such practices and as memory traces orienting the conduct of knowledgeable human agents.<sup>75</sup>

The records continuum model and theory of structuration together provide useful tools for exploring records, at the level of metatheory or grand narratives; and as the product of the relationships between people and social structures. Metatheory and grand narratives “consists of postulates that “are intended to apply over the whole range of human social activity, in any and every context of action”. These are sensitising theories which support the development of a “wide range of perhaps competing substantive theories” within the context of empirical research.<sup>76</sup>

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<sup>70</sup> Giddens, *Social Theory and Modern Sociology*, 60.

<sup>71</sup> Giddens, *The Constitution of Society: Outline of the Theory of Structuration*, 3, as cited in K. Tucker, *Anthony Giddens and Modern Social Theory* (London: SAGE Publications, 1998), 2.

<sup>72</sup> Tucker, *Anthony Giddens and Modern Social Theory*, 2.

<sup>73</sup> Giddens as cited in Bryant and Jary, *Giddens’ Theory of Structuration: A Critical Appreciation*, 1.

<sup>74</sup> R. Sibeon, *Rethinking Social Theory* (London: SAGE Publications, 2004).

<sup>75</sup> Giddens, *The Constitution of Society: Outline of the Theory of Structuration*, 17.

<sup>76</sup> Sibeon, *Rethinking Social Theory*, 14.

In records continuum thinking the record is part of a recursive relationship; the record is the product of and influencing factor within social structure. This is a reflexive relationship in which people and records are constantly interacting and influencing each other. The records continuum model highlights the layers of agency as plurality of perspectives unique and shared. Paradoxically the record's potential is never fully understood but continuously being realised through its construction and reconstruction. Upward draws upon key features within structuration theory to describe the continuum of action-based information processes continuum.<sup>77</sup> These features include:

- Agency and duality of structure<sup>78</sup>
- And, the 'homeostatic feedback loops' which are "causal feedback loops in which the feedback is affected by the actor's knowledge".<sup>79</sup>

When applied to records in the continuum these features, in essence, depict a constant state of creation or more accurately co-creation between people and social structures. The future of a record in continuum thinking is being created in the here and now. The preamble to the *future* is perceived and enacted in the 'create' dimension of the records continuum model through the act of record creation and recordkeeping. This perspective does not obscure the other dimensions or axes of the records continuum model but rather the context creates a frame of reference which like Einstein's *Theory of Relativity* attempts to somehow apply independent of the reference frame. "Einstein's theory does not favour any particular number of dimensions." What seems to be one dimension is really more than one and all dimensions are equally present even when focusing on one. "There are many examples in daily life of objects whose extent in one of the familiar dimensions is too small to be noticed...and the only way to see the three dimensional structure of such things is to look up close, or with sufficiently fine resolution".<sup>80</sup> The *Powers of Ten* (1977) is a short film which aims to illustrate the relative size of things in the universe.<sup>81</sup> The film so simply demonstrates how dimensions in time and space can exist concurrently but perception is dependent on position.

*Powers of Ten* takes us on an adventure in magnitudes. Starting at a picnic by the lakeside in Chicago, this famous film transports us to the outer edges of the universe. Every ten seconds we view the starting point from ten times farther out until our own galaxy is visible only as a speck of light among many others. Returning to Earth with breathtaking speed, we move inward- into the hand of the sleeping picnicker- with ten times more magnification every ten seconds. Our journey ends inside a proton of a carbon atom within a DNA molecule in a white blood cell.<sup>82</sup>

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<sup>77</sup> Upward, "The Records Continuum."

<sup>78</sup> Bryant and Jary, *Giddens' Theory of Structuration: A Critical Appreciation*, 144.

<sup>79</sup> *Ibid.*, 8.

<sup>80</sup> L. Randall, *Warped Passages: Unravelling the Universe's Hidden Dimensions*. (London: Penguin Books, 2006), 33–35, 88. Kindle Edition.

<sup>81</sup> "Powers of Ten. Based on the Film by Charles and Ray Eames. An Eames Office Website," accessed July 27, 2011, <http://www.eamesoffice.com/the-work/powers-of-ten/>; "Powers of Ten – Wikipedia, the Free Encyclopedia," accessed January 3, 2013, [https://en.wikipedia.org/wiki/Powers\\_of\\_Ten\\_%28film%29](https://en.wikipedia.org/wiki/Powers_of_Ten_%28film%29).

<sup>82</sup> *Powers of Ten*<sup>TM</sup> (1977), accessed January 3, 2013, <http://www.youtube.com/watch?v=0fKBhvDjy0>.

As with records creation, dimensions and the axes in the records continuum model are plural. Perspectives are viewed through the eyes of people whether in the personal context or that of institutions. People, as co-creators of records and perspectives, are influenced by complex interpersonal processes, social relationships and meaning, which are not always made explicit. Further to these postmodern archival theories regarding the records continuum, structuration and ‘evidence of me’ in the next section I introduce other conceptualisations of personal records.

### 2.3.4 Postmodern archival paradigms: Personal recordkeeping and ‘evidence of me’

In the preceding sections I have highlighted significant aspects of postmodern archival thinking. For my research it was important to note that records continuum thinking and structuration theory are helpful mechanisms for understanding records and for working with people in society and in their contexts. In this section I link this material to the seminal work of McKemmish related to ‘evidence of me’.<sup>83</sup>

Though there has been much discourse in the archival community, regarding the nature of personal records and their ability to support social relationships, memory and identity for individuals and in the community, there has been limited development and application of theories when co-creating records in applied research contexts. Historically, archives have been associated with the records or artefacts within institutions, and to some extent, the role of records in the lives of individuals and communities to which they pertain.

There is an increasing body of archival theorists who are reconsidering not only the characteristics of the record and the archives, but also the role of records, archives and the archivist in individual, social and cultural contexts.<sup>84</sup> Archival thinking has concurrently been challenged to understand the relationship between records, memory and identity and the inherited responsibilities which are accorded to the way records are created as well as used.

In archival theory, records are distinguished “from other forms of recorded information by their ongoing participation in social, business and other processes, broadly defined, i.e. by their transactional and contextual nature.”<sup>85</sup> Archival discourses have long differentiated between corporate and personal records by way of purpose, use and how they should be managed by the archival profession. In her paper “Evidence of me...”, McKemmish challenged this dualistic discourse through an analysis of recordkeeping behaviour of literary authors in relationship to their writings. Personal records are described in “their broadest

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<sup>83</sup> McKemmish, “Evidence of Me...”; S. McKemmish, “Evidence of Me – in a Digital World,” in *I, Digital: Personal Collections in the Digital Era*, ed. C. A. Lee (Chicago, IL: Society of American Archivists, 2011), 115–49.

<sup>84</sup> L. Craven, *What Are Archives?: Cultural and Theoretical Perspectives: A Reader* (Burlington, VT: Ashgate, 2008), 1.

<sup>85</sup> F. Upward and S. McKemmish, “In Search of the Lost Tiger, by Way of Sainte-Beuve: Re-Constructing the Possibilities in ‘Evidence of Me’.” [Response to Harris, Verne. On the Back of a Tiger: Deconstructive Possibilities in ‘Evidence of Me’,” *Archives and Manuscripts*, 29, no. 1 (2001): 8–21.

sense...all forms that storytelling takes in human society”.<sup>86</sup> McKemmish highlights the powerful urge the individual has to be a witness to self and others by ‘recording’ in some way evidence of ‘me’. Personal recordkeeping is described as “a kind of witnessing” and the records we accumulate whether consciously or unconsciously are “a way of evidencing and memorialising our lives – our existence, our activities and experiences, our relationships with others, our identity, our ‘place’ in the world”.<sup>87</sup>

Personal recordkeeping was explored further by McKemmish, in ‘Evidence of me – in a Digital World’. Personal records were characterised as embodying in some way the voice of the person who created the records.<sup>88</sup> Personal records are part of a continuum which acknowledges the many perspectives that influence the management of records to include “the personal and corporate recordkeeping activities undertaken by individuals in their everyday lives, in families, work or community groups and in organisations of all kinds”.<sup>89</sup> This reflects a continuum view of archives and recordkeeping; with layers of context and meaning that can be associated with a record and that its value is recorded and iterative. Records are part of a continuum in which they are more than physical things; instead they are an “evidentiary and post-custodial reality.”<sup>90</sup> Archivists and recordkeepers are increasingly conscious that their accountability began from the time of the record’s creation.<sup>91</sup>

Harris, in his critique of “Evidence of me...”, argued that McKemmish had constructed a metanarrative in describing the relationships of authors to their personal records: a process which risked distancing the recordkeeping behaviour from the influences of context which could be many and changing.<sup>92</sup> Understanding personal roles, relationships and meaning to records is highly contextual. For each person and record, there are complex relational dimensions which can only understood in the context of their creation and use.

Creating all manner of artefacts is an integral part of being human and these products are records of who we are; and how we engage with the world. “Human nature is not found within the human individual but in the movement between the inside and outside, in the worlds of artefact use and artefact creation.”<sup>93</sup> The postmodern view of the record is that it has no fixed boundaries.<sup>94</sup> Cook explains that the record is a “mediated and ever-changing construction” with multifaceted meanings retained in the interpretation, construction and deconstruction.<sup>95</sup> According to Harris, “the ground is shifting. The words and concepts

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<sup>86</sup> McKemmish, “Evidence of Me – in a Digital World,” 115.

<sup>87</sup> McKemmish, “Evidence of Me...,” 1.

<sup>88</sup> McKemmish, “Evidence of Me – in a Digital World.”

<sup>89</sup> McKemmish, Upward, and Reed, “Records Continuum Model,” 4448.

<sup>90</sup> G. Acland, “Managing the Record Rather Than the Relic,” *Archives and Manuscripts* 20, no. 1 (1992): 57–63, as cited in S. McKemmish, “Are Records Ever Actual?,” in *The Records Continuum*, ed. S. McKemmish and M. Piggott (Ancora Press in association with Australian Archives, 1994), 187–203, <http://www.infotech.monash.edu.au/research/groups/rcrg/publications/smcktrc.html>.

<sup>91</sup> McKemmish, “Are Records Ever Actual?”

<sup>92</sup> V. Harris, “On the Back of a Tiger: Deconstructive Possibilities in ‘Evidence of Me,’” *Archives and Manuscripts* 29, no. 1 (2001), <http://www.mybestdocs.com/harris-v-tiger-edited0105.htm>.

<sup>93</sup> Y. Engeström, R. Miettinen, and R. L. Punamäki-Gitai, *Perspectives on Activity Theory* (Cambridge: Cambridge University Press, 1999), 5.

<sup>94</sup> Ketelaar, “Tacit Narratives,” 138.

<sup>95</sup> Cook, “Archival Science and Postmodernism,” 10.

which are archivists' basic tools are anything but simple, stable and uncontested.” The record and the archive have multiple realities and meaning which challenge the capture and preservation of these rich contexts.<sup>96</sup>

## 2.4 **Conceptualisations of the Personal Record: The Record as Memory**

During the 1990s, the relationships between records, archives and memory were being reconceptualised. Schwartz and Cook explain how archives were being characterised as memory institutions and consequently records as memory.<sup>97</sup> The adoption of this metaphor of memory reflected both the broader theories in psychology and memory studies happening across other disciplines particularly the social sciences. Burr explains that,

The metaphor of things as machines is as much at the root of psychology today as it was in its infancy. Today's cognitive science has the computer as its metaphor for psychological phenomena, just as in the past Freud saw the psyche as operating like a hydraulic system, and the early behaviourists saw the mechanism of the reflex arc as the fundamental principle of human behaviour.<sup>98</sup>

This way of conceptualising records creates concerns regarding the appropriation of “memory concepts in archival science” which “suffers from simplification and overgeneralisation”.<sup>99</sup> Cook acknowledged ‘the problematic and ill-defined use’ of terminology as used in archival literature with regard to memory, identity and archives. This expression of concern described what he considered to be a lack of discrimination in how meaning may change according to the context in which the terminology is applied, and how this is particularly prevalent in traditional archival paradigms.<sup>100</sup>

It is in this pluralistic context where personal recordkeeping creates special concerns for the archival profession regarding the role of the archivist, the creation of new disciplinary knowledge and implications for practice.<sup>101</sup> Personal records and archives according to Hobbs have special characteristics which reflect the inner life of a person beyond that of recorded evidence. Hobbs explains how she departs from the notion of personal records as being purely transactional. The psychology of personal records in this sense, challenges existing

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<sup>96</sup> V. Harris, “Claiming Less, Delivering More: A Critique of Positivist Formulations on Archives in South Africa,” *Archivaria* 1, no. 44 (1997): 135,

<http://journals.sfu.ca/archivar/index.php/archivaria/article/viewArticle/12200>.

<sup>97</sup> J. M. Schwartz and T. Cook, “Archives, Records, and Power: The Making of Modern Memory,” *Archival Science* 2, no. 1 (2002): 1–19.

<sup>98</sup> V. Burr, *The Person in Social Psychology*, (East Sussex: Taylor & Francis e-Library, 2005), 6–7. Kindle Edition.

<sup>99</sup> M. Hedstrom, “Archives and Collective Memory: More than a Metaphor, Less than an Analogy,” in *Currents of Archival Thinking*, ed. T. Eastwood and H. McNeil (Santa Barbara, CA: Libraries Unlimited, 2010), 163.

<sup>100</sup> T. Cook, “Evidence, Memory, Identity, and Community: Four Shifting Archival Paradigms,” *Archival Science* 13, no. 2 (2013): 1–26.

<sup>101</sup> R. J. Cox, *Personal Archives and a New Archival Calling: Readings, Reflections and Ruminations* (Sacramento, CA: Litwin Books, 2008).



theories and practice which are built on models of organisational or government records. What is it that make these records personal and what do they represent?<sup>102</sup>

In life we accumulate, as well as consciously collect the functional, the things of meaning, the memories themselves or what might be considered mnemonic devices for remembering. When these records of self are absent there is still the trace of what happened and memory work is a way of “patching together reconstructions out of fragments of evidence”.<sup>103</sup> “Recordkeeping is a ‘kind of witnessing’. On a personal level it is a way of evidencing and memorialising our lives...our identity, our ‘place’ in the world.”<sup>104</sup> McKemmish gives examples of individuals who accumulate ‘personal records’ over time as part of an archiving process. There are ‘outwards and inwards files’. It is both private and dependent on our external environments. It both shapes and is shaped by our inner and outer worlds. It is possible to identify the roles, functions and activities in personal records just as it is with organisational or institutional records. Personal records help define relationships; relationships beyond those associated with recordkeeping behaviour.

McKemmish describes how individuals have a powerful urge to ‘record’ in some way ‘evidence of me’ and looks to Giddens work on self-identity and modernity with regard to ‘existential questions’. The personal archive is in its “broadest sense – encompassing all forms that storytelling takes in human society”.<sup>105</sup> According to Giddens “a person’s identity is not to be found in behaviour about herself – important though this is – in the reactions of other, but the capacity to keep a particular narrative going”.<sup>106</sup>

There is the drive to tell one’s story, to remember, account and evidence one’s life externally as well as within. The archival community has a longstanding relationship and affinity with Derrida and his work.<sup>107</sup> Derrida describes Freud’s paradox of the archive in which “there is no archive without consignment in an external place which assures the possibility of memorization, of repetition, of reproduction, or of reimpression, then we must also remember that repetition itself, the logic of repetition, indeed the repetition compulsion, remains...indissociable from the death drive. And thus from destruction.”<sup>108</sup>

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<sup>102</sup> C. Hobbs, “The Character of Personal Archives: Reflections on the Value of Records of Individuals,” *Archivaria* 1, no. 52 (2001), <http://journals.sfu.ca/archivar/index.php/archivaria/article/viewArticle/12817>.

<sup>103</sup> A. Kuhn, *Family Secrets: Acts of Memory and Imagination* (London: Verso, 2002), 4.

<sup>104</sup> McKemmish, “Evidence of Me...”

<sup>105</sup> McKemmish, “Evidence of Me – in a Digital World,” 115.

<sup>106</sup> Giddens, *Modernity and Self-Identity: Self and Society in the Late Modern Age*, 54.

<sup>107</sup> V. Harris, “A Shaft of Darkness: Derrida in the Archive,” in *Refiguring the Archive*, ed. C. Hamilton et al. (Dordrecht: Springer Netherlands, 2002), 61–82, [http://dx.doi.org/10.1007/978-94-010-0570-8\\_6](http://dx.doi.org/10.1007/978-94-010-0570-8_6); C. Hamilton and V. Harris, *Refiguring the Archive* (Cape Town: David Philip, 2002); J. Derrida, *Archive Fever: A Freudian Impression*, trans. E. Prenowitz (Chicago, IL: University of Chicago Press, 1998); B. Brothman, “Declining Derrida: Integrity, Tensegrity, and the Preservation of Archives from Deconstruction,” *Archivaria* 48 (January 1999): 64–88; Harris, “Something Is Happening Here and You Don’t Know What It Is: Jacques Derrida Unplugged.”; M. Piggott, “Human Behaviour and the Making of Records and Archives,” *Dimension* 20 (1985): 13–21.

<sup>108</sup> Freud as cited in J. Derrida and E. Prenowitz, *Archive Fever: A Freudian Impression* (Chicago, IL: University of Chicago Press, 1998), 12.

Personal archives contain the personal view of life's experiences; they represent a departure from the collective formality and systematic organisation found in other types of records. Personal fonds contain documentation of individual lives and human personality. While these fonds certainly often reflect the recorded evidence of the functions of the creator, in the same way as to fonds of organisations, personal archives also contain traces of the individual character of the record's creator. There are here glimpses of the inner soul as well as its outer manifestation of public activities.<sup>109</sup>

Personal archives are being reimagined in post-custodial environs which blur the evidential and space-time boundaries by which records and archives have been mostly defined. "In continuum terms, while a record's content and structure can be seen as fixed, in terms of its contextualisation, a record is 'always in a process of becoming'."<sup>110</sup> Upward describes the creation of a record as a creative process and an intersecting dimension of activity. "Records can even have multiple lives in spacetime as the contexts that surround them and control alter and open up new threads of action, involving re-shaping and renewing the cycles of creation and disposition."<sup>111</sup> A record's purpose is not limited to its evidential qualities in a legalistic sense but may be encompassing of other qualities and attributes.<sup>112</sup> The record is "far from being an innocent by-product of activity, [is] a reflection of reality, it is a construction of realities expressing dominant relations of power".<sup>113</sup>

Conceptualising the record as memory encapsulates the importance of records and storytelling in witnessing to our lives and identity. There are many dimensions to these types of records which raises existential questions regarding their meanings. Awareness and care are important in reconciling how records represent and are represented. This is developed theoretically by discussing the three aspects of personal recordkeeping. These are:

- Personal recordkeeping: Many meanings to many people
- A consciousness of perspectives: plurality of the record
- Evolving a participatory epistemology: multiple realities and archival identity

#### 2.4.1 Personal recordkeeping: Many meanings to many people

Depending on the context within which it is perceived, records may have many meanings to many people and at many different times. It is the evidentiary quality of the record from which meaning and informational value is derived.<sup>114</sup> The conceptualisation of the record as memory does in itself illustrate the social nature of knowledge as it is created and transposed. Archival theorists were working within what were then contemporary understandings of memory as a process. Records can represent whatever data and media are used by the creator

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<sup>109</sup> Hobbs, "The Character of Personal Archives," 127.

<sup>110</sup> McKemmish, "Placing Records Continuum Theory and Practice," 335.

<sup>111</sup> Upward, "Modelling the Continuum as Paradigm Shift in Recordkeeping and Archiving Processes, and beyond a Personal Reflection," 119.

<sup>112</sup> Harris as cited in McKemmish, "Placing Records Continuum Theory and Practice," 345.

<sup>113</sup> Harris as cited in E. Ketelaar, "Archives as Spaces of Memory," *Journal of the Society of Archivists* 29, no. 1 (April 2008): 11, doi:10.1080/00379810802499678.

<sup>114</sup> S. McKemmish, "Yesterday, Today and Tomorrow: A Continuum of Responsibility," in *Preserving Yesterday, Managing Today, Challenging Tomorrow: Yesterday, Today and Tomorrow: A Continuum of Responsibility, 15-17 Sept* (Perth, WA, 1997).

to convey meaning.<sup>115</sup> Records differ from other forms of recorded information in that they preserve content with transactional qualities that support ongoing evidential use. The purpose that these records potentially serve is relative to the value they have for individuals, organisations, or society.<sup>116</sup>

Hurley offers the concept of parallel provenance in response to the existing weaknesses in archival description which struggle in more distributed and ubiquitous digital environments. Description should be about “enriching contextualisation” rather than documenting the formation of records and the functions in which they took part. It is about being “socially responsible” and understanding the significance of the stories that are told in the recordkeeping process and particularly provenance. “Recordkeeping is about meaning. The narrative of recordkeeping is about belonging – ownership of the records and the *truth* that records memorialise. It is found in the attributions that archivists call provenance.”<sup>117</sup>

Documenting the stories associated with the records is, according to Hurley, an integral part of achieving the rich archival description that enables the record to transcend the boundaries imposed by current standards and systems. The essence of effective archival description is the accurate capture and maintenance of relationships between events and circumstances. Hurley reinforces the notion that “recordkeeping is about meaning” and contextualising the record requires management of the record in all its eventual contexts. For a record to be accurately represented it must convey both explicit and tacit knowledge to the mind of the observer. “What kind of thing is it that you are seeing represented? And, from what point of view is it being depicted?”<sup>118</sup>

Records need to be understood in order to be described. Describing provenance is complex through a postmodern and inherent social constructionist lens, which challenges singular notions of ownership and transactional processes. Hurley explains, that parallel provenance as a concept and in practice, raises questions regarding how archival material is described and by whom. He encourages archivists to challenge their own assumptions and traditions by reconsidering contexts of ownership, processes and the views represented by records. An archivist needs to be explicitly aware of their own worldviews and conscious of how these views may limit their ability to perceive the perspectives of others.<sup>119</sup>

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<sup>115</sup> I. Maclean, “An Analysis of Jenkinson’s Manual of Archive Administration in the Light of Australian Experience,” in *Debates and Discourses: Selected Australian Writings on Archival Theory 1951–1990*, ed. P. Biskup et al. (Canberra, ACT: ASA, 1995) as cited in S. McKemmish, “Traces: Document, Record, Archive, Archives,” in *Archives: Recordkeeping in Society*, ed. S. McKemmish et al. (Wagga Wagga, NSW: Centre for Information Studies, Charles Sturt University, 2005), 10.

<sup>116</sup> S. McKemmish et al., eds., *Archives: Recordkeeping in Society* (Wagga Wagga, NSW: Centre for Information Studies, Charles Sturt University, 2005), 15–16.

<sup>117</sup> C. Hurley, “Parallel Provenance [Series of Parts]: Part 1: What, If Anything, Is Archival Description?,” *Archives and Manuscripts* 33, no. 1 (2005): 112–113. Emphasis added.

<sup>118</sup> C. Hurley, “Parallel Provenance (If These Are Your Records, Where Are Your Stories?),” n.d., <http://www.infotech.monash.edu.au/research/groups/rcrg/publications/parallel-provenance-combined.pdf>.

<sup>119</sup> C. Hurley, “Parallel Provenance [Series of Two Parts] Part 2: When Something Is Not Related to Everything Else,” *Archives and Manuscripts* 33, no. 2 (November 2005): 52.

The ability for archivists to describe the complexity and plurality of records is dependent on their knowledge and skills in understanding and documenting more than the process of creating records. Bunn highlights how the definitions and descriptions of records provenance are being extended.

Laura Millar (2002) has called for use to “expand our own definition, so that the concept encompasses not just the creation of the records but also their history over time and our role in their management” (p. 12). Chris Hurley (2005), possibly provenance’s most vehement critic, has expanded his own definition to include concepts such as parallel provenance, multiple provenance and simultaneous provenance.<sup>120</sup>

Archival description needs to be able to recognise simultaneous multiple creators of a record with knowledge of their personal identity. Though the tendency is to want to simplify description, articulating roles and relationships to the records creation process is complex.<sup>121</sup> The way we understand personal (human as opposed to organisational) roles, relationships and records, is very much dependent on the worldview and paradigms from within which this knowledge is created. From the point of co-creating person-centred records, two messages have salience. These are: the importance of describing complexity and documenting the process of co-creating records and, the need to understand the associated meanings, perspectives and context of people in representation.

#### 2.4.2 A consciousness of perspectives: Plurality of the record

Goodman acknowledges the existence of ‘*multiple actual worlds*’ rather than ‘alternatives to a single actual world’ and asks difficult questions regarding the nature of *worlds* and how they are related to knowing. He explains how “frames of reference...seem to belong less to what is described than to systems of description; and each of the two statements relates what is described to such a system.”<sup>122</sup>

Records continuum thinking represents a broader spacetime view of the complexity of the recordkeeping world in order to see the relationship of all of its parts. In seeking to redefine the individual they explain how the management of the aggregate also changes.<sup>123</sup> As Bruno Latour et al. hypothesised “the whole is always smaller than its parts” in that “there is more complexity in the elements than in the aggregates”.<sup>124</sup>

One of the key issues in even considering personal recordkeeping as a way of evidencing a person’s life relates to how records, like memory and identity, are never fixed in meaning. They are all continuously evolving. They are subject to the situated and broader contexts. As

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<sup>120</sup> J. Bunn, “Questioning Autonomy: An Alternative Perspective on the Principles Which Govern Archival Description,” *Archival Science* 14, no. 1 (March 2014): 3–15, doi:10.1007/s10502-013-9200-2.

<sup>121</sup> C. Hurley, “Problems with Provenance,” accessed March 31, 2011, <http://www.infotech.monash.edu.au/research/groups/rcrg/publications/provenance.html>.

<sup>122</sup> N. Goodman, *Ways Of Worldmaking* (Indianapolis, IN: Hackett Publishing, 1978), 1–2, <http://books.google.com.au/books?id=Y5aMV3EE6WcC>.

<sup>123</sup> B. Latour et al., “The Whole Is Always Smaller than Its Parts: A Digital Test of Gabriel Tarde’s Monads,” *British Journal of Sociology* 63, no. 4 (2012): 2.

<sup>124</sup> *Ibid.*

McKemmish says records are “always in the process of becoming”.<sup>125</sup> According to McKemmish it is possible to determine the functional requirements of personal records in the manner that corporate records may be analysed.<sup>126</sup> The individuals and their recordkeeping behaviour can be defined “in terms of their relationships with others...and in society”.<sup>127</sup>

The consciousness of there being many perspectives regarding how we think about records according to Ketelaar begins before the record’s conception. Ketelaar coined the term ‘archivalization’ to signify the “conscious or unconscious choice (determined by social and cultural factors) to consider something worth archiving”.<sup>128</sup> It precedes archiving and acknowledges the role of the archivist in all the recordkeeping processes including their purposeful creation.<sup>129</sup>

Describing the multiple realities of records in their creation and in their relationships to people as well as other records is complex. The archive is the convergence of overlapping worlds. It is porous to the interventions it sustains. It creates tension between ways of knowing and sharing. It is open-ended and speaks with many voices. It claims to be memory and identity of the individual and society. It remembers and forgets. It distorts the absence by privileging presence. It challenges the notion of embodiment in a physical form. It is evidence of authoritative choices and underprivileged actors. It resists change and struggles to maintain the context. Ownership and objectivity are contested. It can be emotive and numbing at the same time. When the records break out they have the capacity to shatter the perceptions within and without.

Gilliland describes how interdisciplinary studies and postmodernism, postcolonialism as well as professional and research interests have influenced the archival turn where archives are signified as both the noun and the verb. This shift to theorising the archive as a gerund highlights the nature of the archive as a process of doing and actively engaging in the creation of records. This emphasis on the postmodern heightens the realisation that archives rather than being a physical site, are the production of and relationship with records.<sup>130</sup>

Cross-disciplinary approaches to understanding the significance of records and archives in the context of broader global challenges has led to what anthropologist Ann Stoler describes as the ‘archival turn’. The archival turn is born out of the postcolonial understanding of the archive and recordkeeping in which archives are “not sites of knowledge retrieval but sites of knowledge production.”<sup>131</sup> Here archives are reimagined to where they are not ‘inert sites of storage and conservation’ but “are concerned with the legitimating social coordinates of

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<sup>125</sup> McKemmish, “Are Records Ever Actual?”

<sup>126</sup> McKemmish, “Evidence of Me...”

<sup>127</sup> Ibid., 30.

<sup>128</sup> Ketelaar, “Tacit Narratives,” 133.

<sup>129</sup> E. Ketelaar, “Archivalisation and Archiving,” *Archives and Manuscripts* 27, no. 1 (1999): 57.

<sup>130</sup> A. Gilliland, “Afterword: In and out of the Archives,” *Archival Science* 10, no. 3 (January 2011): 334–336, doi:10.1007/s10502-010-9134-x.

<sup>131</sup> A. L. Stoler, “Colonial Archives and the Arts of Governance,” *Archival Science* 2, no. 1 (2002): 87.

epistemologies: how people imagine they know what they know and what institutions validate that knowledge, and how they do so”.<sup>132</sup>

The ‘archival multiverse’ is a term coined by Ally Krebs through the activities of the Archival Education and Research Institute (AERI) which has been conducted annually since 2009 in the United States of America. Participants in the AERI included influential Australian archival theorists, whose work has focused on understanding the multiple dimensions of records and archives. It was the ‘Pluralizing the Archival Curriculum Group’ who applied a continuum based view in order to disrupt the corporate/personal duality which is woven through archival discourse and this has had a profound influence on both archival theory and practice.

In their 2013 paper McKemmish and Piggott clarify that “evidentiary texts are inclusive of ‘records as they exist in multiple cultural contexts’ and all forms of recordkeeping, including the institutional/bureaucratic and the personal”.<sup>133</sup> This search for new ways of knowing and understanding the world, challenges and extends the archival discourse to be inclusive of diversity. The archival multiverse encapsulates in its definition “the pluralism of evidentiary texts, memory-keeping practices and institutions, bureaucratic and personal motivations, community perspectives and needs, and cultural and legal constructs with which archival professionals and academics must be prepared, through graduate education, to engage.”<sup>134</sup>

There has been limited archival research in the study of personal recordkeeping in societal contexts, which fall outside of traditional organisational and institutional archives, where the dominant layers of infrastructure, function and hierarchy are less evident. This raises important questions about how archivists as a discipline know and understand the phenomena of the personal record and its meaning through the postmodern worldview where records are characterised as a “special genre of documents in terms of their intent and functionality”.<sup>135</sup> Understanding records in their intent and functionality requires understanding the worldview of the record creators. A worldview is not a model that can be enforced as a way of seeing rather it is described as “a non-rational foundation for thought, emotion, and behaviour...an individual’s accepted knowledge, including values and assumptions, which provide a ‘filter’ for the perception of all phenomena”.<sup>136</sup>

Investigating the realities and meaning of personal records in the context of the person with early stage dementia required entering into their unique world to understand the impact of impaired memory on identity. Dementia is not just disease of the brain but affects the whole person, physically and psychologically. It is confronting due to the ‘perceived’ changes that occur in people with the disease. It is in part about what is happening for the person, and

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<sup>132</sup> Ibid., 95.

<sup>133</sup> S. McKemmish and M. Piggott, “Toward the Archival Multiverse: Challenging the Binary Opposition of the Personal and Corporate Archive in Modern Archival Theory and Practice,” *Archivaria* 76, Fall (2013): 113.

<sup>134</sup> Pluralizing the Archival Curriculum Group (PACG), “Educating for the Archival Multiverse,” *The American Archivist* 74, no. 1 (2011): 73.

<sup>135</sup> McKemmish, “Placing Records Continuum Theory and Practice,” 335.

<sup>136</sup> J. D. Glazier and R. Grover, “A Conceptual Framework for Theory Building in Library and Information Science,” *Library and Information Science Research* 50, no. 3 (2002): 235.

possibly a larger part in the way others believe that person to be changed.<sup>137</sup> For the person with dementia there is the inherent imperative to sustain memory and support identity in a way that respects unique and complex contextual dimensions. Records are one way of communicating personal memories and subjective experience.

### 2.4.3 Evolving a participatory epistemology: Multiple realities and archival identity

Multiple eras of archival science have generated different methods and approaches to theory and practice. As my research is of a postmodern epistemology, it is important to locate this within the overall paradigmatic approaches associated with each of the eras.

In this postmodern context of working across disciplines and with people diagnosed with dementia, there were many underpinning assumptions in concepts which I encountered. These assumptions were powerful influences in epistemology within this research; that is the way we know and understand reality.

Epistemologies are theories, beliefs, and assumptions about the ways we can learn about the world. They consider the relationship between the knower and the known and how valid knowledge is created...Epistemologies and ontologies are not motives or points of origin for behaviour; rather, they are integral (and often assumed) conceptual parameters that render particular course of action more plausible, or implausible, than others. The epistemic foundation of social research directs our attention to certain “realities” and not to others and thereby determines the horizon of possibilities for any research project – what can and cannot be seen as well as what can and cannot legitimately be argued...ontological and epistemological foundations establish strategies for recognizing, collecting, and analysing data. They also provide conceptual commitments that include the nature and possibilities of subjectivity, agency, and experience.<sup>138</sup>

Epistemological assumptions included, at a minimum, the presumed bodies of knowledge embodied within the numerous communities in which I participated. As Harris explains “One’s understanding of and feeling for a concept inevitably are shaped by the weighting of one’s experience. Experience is never unmediated. Discourse, ideas, language, all shape how living is turned into experience.”<sup>139</sup> Assumptions are like a foreign language; the researcher must learn of the origins of theory and how we know in order to understand how concepts and their meanings are positioned as part of a continuum.

As discussed earlier in this section, in the field of archival science there is recognition of the power of the record, on the lives of individuals and communities, particularly in the ways that

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<sup>137</sup> J. C. Hughes, S. J. Louw, and S. R. Sabat, *Dementia: Mind, Meaning, and the Person*, International Perspectives in Philosophy and Psychiatry (Oxford: Oxford University Press, 2006).

<sup>138</sup> C. M. Pascale, *Cartographies of Knowledge: Exploring Qualitative Epistemologies* (Thousand Oaks, CA: Sage Publications, 2010), 29–30.

<sup>139</sup> V. Harris, “The Archival Sliver: Power, Memory, and Archives in South Africa,” *Archival Science* 2, no. 1 (2002): 63.

records are constructed and perceived in diverse social contexts.<sup>140</sup> Contemporary culture is challenging perceptions of the record as a construct to provoke what Gergen describes as the “collapsing of traditional categories...genres are continuously blurring, blending, and reforming...Words are not mirrorlike reflections of reality, but expressions of group convention...their values, politics, and ways of life.”<sup>141</sup>

In his 2012 paper, Cook examined archival paradigms as they have evolved to reflect the archival community, over the previous century. Archivists are progressively reinterpreting their identity, their roles in relationship to records and archives in broader social contexts. In the space of a century archivists have repositioned themselves and their “frameworks for thinking”.<sup>142</sup> Archival tradition and theory has until more recently sustained the role of archivist as being that of “keeper” or care taker of records. Cook challenges archival professionals not to diminish the profession but rather “reconceptualizing traditional strengths of professionals” in their roles and responsibilities.<sup>143</sup>

As described earlier in this chapter, paradigms evolve as a set of ontological and epistemological assumptions which

socialize those living in a specific time and form the basis for how individual understand themselves and how they make sense of the events occurring in the world. These basic assumptions support certain ways of understanding, knowing, and behaving (they are logical with the prevailing assumptions) and discourage others (which are illogical within the prevailing assumptions).<sup>144</sup>

Cook describes how professional archival identity, practice and inherent assumptions continue to evolve through emergent digital environments into a postcustodial era; with a “conceptual paradigm of logical or virtual realities”. In this postcustodial era, records are the processes

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<sup>140</sup> The contexts explored in archival literature are plentiful and varied. Examples include: J. Sassoon and T. Burrows, “Minority Reports: Indigenous and Community Voices in Archives. Papers from the 4th International Conference on the History of Records and Archives (ICHORA4), Perth, Western Australia, August 2008,” *Archival Science* 9, no. 1 (2009): 1–5, doi:10.1007/s10502-009-9097-y; A. Flinn, M. Stevens, and E. Shepherd, “Whose Memories, Whose Archives? Independent Community Archives, Autonomy and the Mainstream,” *Archival Science* 9, no. 1 (2009): 71–86; M. Caswell, “Toward a Survivor-Centered Approach to Records Documenting Human Rights Abuse: Lessons from Community Archives,” *Archival Science* 14, no. 3 (2014): 307–22, doi:10.1007/s10502-014-9220-6; S. Yaco et al., “A Web-Based Community-Building Archives Project: A Case Study of Kids in Birmingham 1963,” *Archival Science* 15, no. 4 (2015): 399–427, doi:10.1007/s10502-015-9246-4.

<sup>141</sup> K. J. Gergen, *The Saturated Self: Dilemmas of Identity in Contemporary Life* (New York: Basic Books, 2000), 119.

<sup>142</sup> Cook, “Evidence, Memory, Identity, and Community,” 97.

<sup>143</sup> T. Cook, “Electronic Records, Paper Minds: The Revolution in Information Management and Archives in the Post-Custodial and Post-Modernist Era,” *Archives and Social Studies: A Journal of Interdisciplinary Research* 1 (March 2007): 401.

<sup>144</sup> K. J. Gergen, “The Social Constructionist Movement in Modern Psychology,” *American Psychologist* 40, no. 3 (1985): 266–75, doi:10.1037/0003-066X.40.3.266, as cited in T. L. Sexton, “Constructivist Thinking within the History of Ideas: The Challenge of a New Paradigm,” in *Constructivist Thinking in Counseling Practice, Research, and Training*, ed. T. L. Sexton and B. L. Griffin (New York: Teachers College Press, 1997), 4–5.



and products of multiple creators in complex environments.<sup>145</sup> Traditions and assumptions are being questioned and critiqued. New conversations are emerging in relation to assumptions which still prevail as part of a continuum. Galloway maintains “the postmodern cultural arena...does not wholly displace premodern and modern practices, just as modern culture has not wiped out premodern practices. People don’t cease.”<sup>146</sup> Postmodernism is not a single movement but rather the activities of many communities. Conceptually postmodernism challenges us to think differently about the way we experience and know the world. Postmodern thinking has, in research, created new ways of understanding the lived experience which challenge notions of certainty regarding what is known.<sup>147</sup>

Modernity, as a cultural influence, in Giddens’s ‘runaway world’ is a dynamic where social change, both in ‘scope and profoundness’, is accelerated and accentuated.<sup>148</sup> Bauman describes this constantly shifting and changing world as Liquid Modernity and its malleability creates challenges and maintaining some sort of form requires more energy and attention.<sup>149</sup> According to Cook there are four key phases in the evolution of archival paradigms:

- Phase 1: Premodern
- Phase 2: Modern
- Phase 3: Postmodern
- Phase 4: Participatory.<sup>150</sup>

If we consider Galloway’s words in this broader context it is possible to see the correlation between the way archivists perceive themselves and their relationship to other communities in a participatory epistemology. The participatory paradigm is the product of the archival community’s cumulative experience both within and outside the discipline. I constructed Table 2 to explore the characteristics of the Cook’s archival era with Sexton’s eras of human believing. According to Sexton, paradigms are the “eras of human believing” that is the eras of scientific and academic thinking which have been described by theorists in the broader academy, outside archival science.<sup>151</sup> The first four columns of Table 2 provide an overview of Cook’s descriptions of the archival role in relation to the relative position of a participatory epistemology within archival paradigms situated in the broader scientific communities.<sup>152</sup> The latter two columns help understand how these paradigms are positioned in the broader academy.

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<sup>145</sup> T. Cook, “The Concept of the Archival Fonds in the Post-Custodial Era: Theory, Problems and Solutions,” *Archivaria* 35, Spring (1993): 26–30.

<sup>146</sup> P. Galloway, “Oral Tradition in Living Cultures: The Role of Archives in the Preservation of Memory,” in *Community Archives: The Shaping of Memory*, ed. Galloway and B. Alexander (London: Facet, 2009), 81.

<sup>147</sup> J. F. Gubrium and J. A. Holstein, *The New Language of Qualitative Method* (Oxford: Oxford University Press on Demand, 1997), 75–76.

<sup>148</sup> A. Giddens, *Runaway World* (London: Profile Books, 2011), [https://books.google.com.au/books?id=dYC2SdogrxnC&printsec=frontcover&source=gbs\\_ge\\_summary\\_r&cad=0#v=onepage&q&f=false](https://books.google.com.au/books?id=dYC2SdogrxnC&printsec=frontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false).

<sup>149</sup> Z. Bauman, *Liquid Modernity* (Cambridge: Wiley, 2013), <https://books.google.com.au/books?id=xZ0RAAAQBAJ>.

<sup>150</sup> Cook, “Evidence, Memory, Identity, and Community,” 97.

<sup>151</sup> Sexton, “Constructivist Thinking within the History of Ideas: The Challenge of a New Paradigm,” 7.

<sup>152</sup> Cook, “Evidence, Memory, Identity, and Community.”

**Table 2 Comparison of archival era in relation to eras of human believing**

Phase	Archival Era (According to Cook)	Description of archivist's role and identity (according to Cook) <sup>153</sup>	Qualities of archival paradigm and concepts (according to Cook) <sup>154</sup>	Eras of human believing (According to Sexton) <sup>155</sup>	Era
1	Pre-modern	"Evidence: pre-modern archiving – the custodian archivist guards the juridical legacy"	Guardianship Impartial custodian Records as evidence Juridical legacy	Dualism Idealism Rationalism	1
2	Modern: 1970s onwards	"Memory: modern archiving – the historian-archivist selects the archive"	Historian-archivist Supporting historians History from the bottom up Attention to individual citizens and groups Active selector of the archive. Conscious creator of public memory	Empiricism Logical positivist/scientific method Objective truth/universal properties. Validity	2
3	Postmodern	"Identity: postmodern archiving – the mediator-archivist shapes the societal archive"	Professional expert Mediator archivist Societal archive Unique professional identity and discipline. Experts in the nature of records and archives as well as the contexts in which they are created.	Constructive reality <b>Participatory epistemology</b> Viability	3
4	Participatory	"Community: <b>participatory</b> archiving – the activist-archivist mentors collaborative evidence and memory-making"	The community takes control of their own records by being active agents in creating and representing their own perspectives and identity. Focus is on working within communities rather than external archives.		

These complementary discourses shed light on how archival roles are changing. A participatory epistemology is influencing practice in archival identity while illuminating the ways knowledge is constructed. Phases/eras 3 and 4 of this comparative table are of particular interest in this context of applied archival research. Archival researchers are describing an era of participatory archiving, extending from the postmodern era and into a paradigm where

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<sup>153</sup> Ibid., 106–113.

<sup>154</sup> Ibid., 106–116.

<sup>155</sup> Sexton, "Constructivist Thinking within the History of Ideas: The Challenge of a New Paradigm," 6.

communities are active agents in the construction and use of records.<sup>156</sup> As Cook explains archivists are emerging to take on the role of advocate and collaborator.<sup>157</sup>

This second generation grounded theory research was positioned within phase 3 archival era (as described by Cook), and constructivist reality with its participatory epistemology (described by Sexton). It was a conscious decision to undertake second generation grounded theory, rather than participatory archival research as explicated in the phase 4 archival era or participatory action research. This was exploratory research in a new context for archival research. When working with participants with dementia I could not assume their level of agency. These decisions were however based on a participatory paradigm and epistemology, as an extension of constructivism.<sup>158</sup>

The postmodern phase according to Cook was pivotal in shifting the way archivists perceived society and in turn this changed the archival paradigm. “There was no “Truth” to be found or protected in archives, but many truths, many voice, many perspectives, many stories.”<sup>159</sup> As Sexton explains, the postmodern perspective is congruous with a “participatory epistemology that replaces the “modern” principle of validity with a constructivist concept of viability. The perspective of the observer and the object of observation are inseparable; the nature of meaning is relative; phenomena are context-based; and the process of knowledge and understanding is social, inductive, hermeneutical, and qualitative.”<sup>160</sup>

The social and intersubjective nature of epistemology, which is already embodied in the work of influential thinkers such as Kuhn, Foucault, Latour and Woolgar, emerge as critical characteristics of social epistemology.<sup>161</sup> The implications of a social epistemology have been described, by Furner and Ketelaar, within archival literature as having a profound effect on how we understand records and their meaning. Records are cultural artefacts and hence it is their meaning which must be understood. Records as “information resources, do not ‘have’ meanings. Rather, different meanings are assigned to the same resource by different people at different times, and that “the” conventional meaning of a given resource is a matter of intersubjective consensus.” Meanings are assigned to records by the relationships with people and within particular contexts.<sup>162</sup>

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<sup>156</sup> M. Stevens, A. Flinn, and E. Shepherd, “New Frameworks for Community Engagement in the Archive Sector: From Handing over to Handing on,” *International Journal of Heritage Studies* 16, no. 1–2 (January 1, 2010): 59–76, doi:10.1080/13527250903441770.

<sup>157</sup> Cook, “Evidence, Memory, Identity, and Community.”

<sup>158</sup> For an in-depth discussion on the evolution of a participatory epistemology in qualitative research see Y. S. Lincoln, S. A. Lynham, and E. G. Guba, “Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited,” in *The SAGE Handbook of Qualitative Research*, ed. N. K. Denzin and Y. S. Lincoln (Thousand Oaks, CA: SAGE Publications, 2011).

<sup>159</sup> Cook, “Evidence, Memory, Identity, and Community,” 16.

<sup>160</sup> Sexton, “Constructivist Thinking within the History of Ideas: The Challenge of a New Paradigm” as cited in Gergen, “The Social Constructionist Movement in Modern Psychology,” 8.

<sup>161</sup> A. Goldman and T. Blanchard, “Social Epistemology,” in *The Stanford Encyclopedia of Philosophy*, ed. E. N. Zalta, 2015, <http://plato.stanford.edu/archives/sum2015/entries/epistemology-social/>.

<sup>162</sup> J. Furner, “Conceptual Analysis: A Method for Understanding Information as Evidence, and Evidence as Information,” *Archival Science* 4, no. 3–4 (December 1, 2004): 233–65, doi:10.1007/s10502-005-2594-8; E. Ketelaar, “Cultivating Archives: Meanings and Identities,” *Archival Science* 12, no. 1 (March 2012): 23, doi:10.1007/s10502-011-9142-5.

Contemporaneously, the emergent characteristics of a distinct participatory paradigm and epistemology has also been discussed, within the context of qualitative research, by Lincoln, Lynham and Guba in relation to the work of Heron and Reason.<sup>163</sup> These discourses explicate how a participatory epistemology is part of a continuum of paradigm positions which are evolving: positivism, postpositivism, critical theories, constructivism and more recently participatory.<sup>164</sup>

The characteristics of a participatory epistemology are informed by postmodern and social constructionist thinking. Lincoln, Lynham and Guba put forward the constructionist position as encompassing these paradigms not as distinct from other paradigms but rather as a relationship:

the criteria for judging either “reality” or validity are [not] absolutist (Bradley & Shaefer, 1998); rather, they are derived from community consensus regarding what is “real”: what is useful and what has meaning (especially meaning for action and further steps) within that community, as well as for that particular piece of research (Lather, 2007; Lather & Smithies, 1997). We believe that a goodly portion of social phenomena consists of the meaning-making activities of groups and individuals around those phenomena. The meaning making activities themselves are of central interest to social constructionists and constructivists simply because it is the meaning-making, sense-making, attribution activities that shape action (or inaction). The meaning-making activities themselves can be changed when they are found to be incomplete, faulty (e.g., discriminatory, oppressive, or nonliberatory), or malformed (created from that can be show to be false).<sup>165</sup>

A participatory epistemology assumes that knowledge is co-constructed and this has implications for *how* we know and then construct new knowledge. Postmodernism and its relationship to the construction of knowledge and understanding in *how* we think, has evolved through the introduction of constructivist thinking in psychological inquiry.<sup>166</sup> It is this constructivist influence and paradigm shift which sees the archivists and recordkeepers acknowledging their own agency as well as the agency of communities in how and why records are created.

The reality of records is that they exhibit plurality of perspectives in all aspects of their expression, matter and behaviour. A key challenge for archival science lies in how we can respect and represent these characteristics so as to fulfil the potential of the record in its multiverse of contexts and meanings and yet protect the rights of those captured in the records or the recordkeeping system. As explored earlier in this chapter, in the 1990s archival

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<sup>163</sup> Lincoln, Lynham, and Guba, “Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited”; J. Heron and P. Reason, “A Participatory Inquiry Paradigm,” *Qualitative Inquiry* 3, no. 3 (September 1, 1997): 274–94, doi:10.1177/107780049700300302.

<sup>164</sup> Lincoln, Lynham, and Guba, “Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited.”

<sup>165</sup> N. K. Denzin and Y. S. Lincoln, “Paradigms and Perspectives,” in *The SAGE Handbook of Qualitative Research* (Thousand Oaks, CA: SAGE Publications, 2011), 115.

<sup>166</sup> Gergen, “The Social Constructionist Movement in Modern Psychology”; N. K. Denzin and Y. S. Lincoln, *The Handbook of Qualitative Research* (Thousand Oaks, CA: SAGE Publications, 2000).

theorist Frank Upward began to build the theoretical foundations for the records continuum model as framework and a tool “to communicate evidence-based approaches to archives and records management.”<sup>167</sup> His work highlights the influence of continuum thinking and postmodern theory on our understanding of the nature of the archive and the record. It has created an awareness of the infinite forms that the record and archive may take through revealing the complex contexts in which records are created or co-created and the possible purposes for their use.<sup>168</sup>

Within a postmodern landscape there is already much scepticism regarding what reality is, does it exist and if so, how might it be represented.<sup>169</sup> Postmodernism attunes us to the subjectivity of what is perceived and how it is represented to draw attention to that which is omitted. If we are to the very extreme, as Lyotard suggests, representing the unrepresentable, then what are the implications for those products of human interaction often described as reality, truth or evidence?<sup>170</sup> This concept of representation is particularly relevant when exploring the concept of records, within new research contexts for archival science, as cultural constructs which are profoundly influenced by the culture.

In conclusion, I have argued the place of this research in the postmodern era of archival science. I have positioned a participatory epistemology as a foundational tenet of this postmodern approach. This section highlights the confluence of the postmodern archival theories and practice which are discussed in Section 2.3. In the following sections I link this postmodern approach and thinking to concepts and the context of dementia. Multiple eras of archival science have generated different methods and approaches to theory and practice. As my research is of a postmodern epistemology, it is important to locate this within the overall paradigmatic approaches associated with each of the eras.

## **2.5 The Situated Context: The Person with Dementia**

Like breathing, remembering is embedded in how we live. We notice it most in its absence, when the activity is interrupted or ceases. For the person with early stage dementia the signs of disease may be barely noticeable. It progresses slowly. The “loss of cognitive function with forgetfulness” precedes other symptoms.<sup>171</sup> We all forget things. We have ways of coping when we do. When an inability to cope in light of lost moments occurs it is impossible to take memories for granted. It is their presence and their absence which reminds us of what is happening and who we are.

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<sup>167</sup> Upward, “Modelling the Continuum as Paradigm Shift in Recordkeeping and Archiving Processes, and beyond a Personal Reflection,” 1.

<sup>168</sup> McKemmish, “Evidence of Me – in a Digital World.”

<sup>169</sup> Gubrium and Holstein, *The New Language of Qualitative Method*, 87.

<sup>170</sup> J. F. Lyotard, *The Postmodern Condition: A Report on Knowledge*, trans. G. Bennington and B. Massumi (Manchester: Manchester University Press, 1984).

<sup>171</sup> J. C. Hughes, S. J. Louw, and S. R. Sabat, “Seeing Whole,” in *Dementia: Mind, Meaning, and the Person*, International Perspectives in Philosophy and Psychiatry (Oxford: Oxford University Press, 2006).

Drawing on postmodern epistemology in this archival research it is important to identify the significance of the situated context and how this relates to the person with dementia. This is discussed using two headings. These are:

- Perceptions of dementia and personhood
- A postmodern paradigm: The person with dementia and personhood.

A review of archival literature failed to identify any reported archival studies in this specific area of personal records and working with people with dementia. This section has been written generically and influenced by Kitwood's influential text *Dementia Reconsidered: The person Comes First*, and from contemporary sources on dementia such as DeBaggio's *Losing my mind: An intimate look at life with Alzheimer's* and Robinson's *Should People with Alzheimer's Disease Take Part in Research?*<sup>172</sup>

As one of the grand challenges in mental health dementia is, contrary to popular belief, not a natural part of ageing.<sup>173</sup> Dementia is complex and multi-dimensional in how it manifests. Scientists have clues as to the causes of dementia but as yet no cure.

Dementia is not one condition but a term encompassing a range of conditions characterised by impairment of brain functions, including language, memory, perception, personality and cognitive skills (AIHW, 2007). Dementia can lead to loss of intellect, rationality, social skills and normal emotional reactions (Alzheimer's Australia, 2009). Conditions associated with dementia are typically progressive, degenerative and irreversible, for which there is currently no cure... There are many types of dementia, the most common form of dementia is Alzheimer's disease which accounts for 50% of all dementia.<sup>174</sup>

Though the incidence of dementia increases with age, particularly for those over 65 years of age, it does also occur with increasing frequency in younger people. Recent studies on the prevalence of dementia, demonstrate that due to cultural and linguistic differences, the current statistics and predictions may seriously underestimate the actual incidence.<sup>175</sup> Jorm et al. applied estimates to population projections for Australia which were prepared by the United Nations for 2000–2050. They reported that the projected number of people with dementia would increase by 241% between the year 2000 and

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<sup>172</sup> Kitwood, *Dementia Reconsidered: The Person Comes First*, (Buckingham: Open University Press, 1997); T. DeBaggio, *Losing My Mind: An Intimate Look at Life with Alzheimer's*, (New York: Free Press, 2003) Kindle Edition.; E. Robinson, "Should People with Alzheimer's Disease Take Part in Research?" in *The Perspectives of People With Dementia: Research Methods and Motivations*, ed. H. Wilkinson (London: Jessica Kingsley Publishers, 2002).

<sup>173</sup> P. Y. Collins et al., "Grand Challenges in Global Mental Health," *Nature* 475, no. 7354 (July 6, 2011): 27–30, doi:10.1038/475027a.

<sup>174</sup> Alzheimer's Australia, *Keeping Dementia Front of Mind: Incidence and Prevalence 2009–2050* (Alzheimer's Australia, 2009), 2, <http://www.accesseconomics.com.au/publicationsreports/search.php?searchfor=dementia+australia&from=0&search=Go>.

<sup>175</sup> Alzheimer's Australia, *Keeping Dementia Front of Mind: Incidence and Prevalence 2009–2050*.

2050. This percentage represents an increase from 172,000 known cases of dementia in 2000 to 588,000 cases in 2050.<sup>176</sup>

In 2010 Australia became the first country in the world to make dementia a National Health Priority.<sup>177</sup> This is in recognition of the burden that dementia places on the families and community, health and residential care as well as associated productivity losses. The socio-economic burden on society has been described as a ‘moral burden’, in light of the ethical decisions that are made, in both formal and informal settings, and which fall predominantly on the carer.<sup>178</sup> These priorities are representative of influential paradigms and discourses in society as well as research.

### 2.5.1 Perceptions of dementia and personhood

The experiences of person with dementia are disparate and sometimes contested. A powerful example of one of these paradigms is Descartes notion of Cartesian dualism in which mind and body are separated.<sup>179</sup> Society’s perceptions of people with dementia have historically been grounded in the medical model where the focus is not on the person but rather the diseased brain. The medical model has historically reinforced the belief that in the case of the person with dementia, the person is being lost as their memory and cognitive capacity diminishes. The individual’s identity is perceived as changing or disappearing.

This paradigm has manifested in a poor understanding of the subjective experience of the person with dementia, and an increase in the associated stigma and inequalities in social relations.<sup>180</sup> These negative effects impact not only on the way the person with dementia is perceived by other people but also the way that they see themselves. According to Sabat the only way to change these negative dynamics is to change the way we perceive people with dementia. It is *our* responsibility to learn to see the person with dementia as having “valid experiences and whose behaviour is driven by meaning”.<sup>181</sup>

So what does it mean to understand and validate the subjective experience and meaning in the context of this research? Philosophically and practically speaking, Sabat’s words affirm my fundamental intent to design this research so that it was person-centred and respectful of personhood. If this research is to understand the concept of the personal record for the person with dementia then the research must focus on the person’s needs and their perceptions. The person with dementia needs to be the principal stakeholder. This focus on

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<sup>176</sup> A. F. Jorm, K. B. Dear, and N. M. Burgess, “Projections of Future Numbers of Dementia Cases in Australia with and without Prevention,” *Australian and New Zealand Journal of Psychiatry* 39, no. 11–12 (2005): 949–63.

<sup>177</sup> Alzheimer’s Australia, *Keeping Dementia Front of Mind: Incidence and Prevalence 2009–2050*, 89.

<sup>178</sup> C. Baldwin et al., “Ethics and Dementia: The Experience of Family Carers,” *Progress in Neurology and Psychiatry* 8, no. 5 (2004): 24–28.

<sup>179</sup> Pascale, *Cartographies of Knowledge: Exploring Qualitative Epistemologies*.

<sup>180</sup> H. Wilkinson, ed., *The Perspectives of People With Dementia: Research Methods and Motivations* (London: Jessica Kingsley Publishers, 2002), 13.

<sup>181</sup> S. R. Sabat, “Excess Disability and Malignant Social Psychology: A Case Study of Alzheimer’s Disease,” *Journal of Community & Applied Social Psychology* 4, no. 3 (1994): 157–66, doi:10.1002/casp.2450040303, as cited in Wilkinson, *The Perspectives of People With Dementia: Research Methods and Motivations*, 11.

the person brings me to critically examine the experience of who we are in the world around us. If we experience ourselves in and through those around us, then how I conducted this research and the relationships I developed with participants, would have a direct influence on the people I was working with as well as the research data or findings.

What would it mean to do research that is person-centred, so that the person is acknowledged as being more than the sum of their situated contexts? Person-centredness is an action which focuses on individual subjectivity rather than the categories by which a person is defined. Tom Kitwood was the Leader of the Bradford Dementia Group in the U.K. and Senior Lecturer in Psychology when he published his book *Dementia Reconsidered: The Person Comes First*. He was considered a pioneer in the field of caring for people with dementia.<sup>182</sup> His work is part of a broader discourse which has continued to give meaning to personhood particularly in the context of dementia care. Kitwood's work was significant because it challenged the predominant medical model of the person with dementia by crystallising a holistic approach to understanding their subjective experience. Each person is unique and as such their life, memories, and experience cannot be generalised.<sup>183</sup> What it means to be a person for Kitwood is ascribed in his definition of personhood: "It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically tested."<sup>184</sup>

Kitwood's work challenged existing discourses and paradigms, regarding perceptions of the person with dementia, which influenced the way we understand being human and how human beings are perceived in practice.<sup>185</sup> Within contemporary theories of identity, self and personhood, the person is not lost. This disjunct between what is happening for the person with dementia and the way they are perceived by others has been described as being due to others not keeping up with the nature of changes occurring for the person experiencing the disease. This separation of mind and body is challenged by theorists, such as Harré, Kitwood, Sabat and Ricoeur, for whom understanding personhood and the self requires a holistic and experiential approach to what it means to be human.<sup>186</sup>

As Kitwood advocates, personhood is what makes a person unique; how we make sense of the world and our place in it. The nature of personhood and identity is complex. There are no singular definitions of these terms, but rather discourses on what is understood through distinct and yet sometimes blurred disciplinary lenses. In the context of this research I have positioned myself and this thesis with regard to the concepts of personhood, person-centredness and identity; not as discrete activities but rather constructed through discourses

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<sup>182</sup> L. Fox, "Obituary: Professor Thomas Kitwood," *The Independent*, January 6, 1999, <http://www.independent.co.uk/arts-entertainment/obituary-professor-thomas-kitwood-1045269.html>.

<sup>183</sup> Kitwood, *Dementia Reconsidered: The Person Comes First*.

<sup>184</sup> *Ibid.*, 8.

<sup>185</sup> Kitwood, *Dementia Reconsidered: The Person Comes First*.

<sup>186</sup> P. Ricoeur, *Oneself as Another*, trans. K. Blamey (Chicago, IL: University of Chicago Press, 1994); R. Harré, *The Singular Self: An Introduction to the Psychology of Personhood* (London: SAGE Publications, 1998); S. R. Sabat, *The Experience of Alzheimer's Disease: Life Through a Tangled Veil* (Oxford: Blackwell Publishers, 2001); Kitwood, *Dementia Reconsidered: The Person Comes First*.



which are expressions of socially constructed reality; they are experienced; shared by participants and the researcher in a reflexive relationship. Rather than mind and matter being different, the person with dementia is a whole being, inseparable and unitary.<sup>187</sup>

Respecting personhood is an approach to validating the embodied experience of each participant. Identity is the way people “make sense of themselves, of their activities, of what they share with others and how they differ from them.”<sup>188</sup> I am therefore, as researcher and a fellow human being, mindful of the way in which my engagement with participants will impact reciprocally on the way we perceive each other. Kitwood states clearly that when we talk about people they should not be referred to or categorised by the disease descriptors which were so much a part of the medical model. This use of language is a “reflection of the values that have prevailed and of the priorities that were traditionally set in assessment, care practice and research... There is an imperative to recognise men and women who have dementia in their full humanity. Our frame of reference should no longer be person-with-DEMENTIA, but PERSON-with-dementia.”<sup>189</sup> When I refer to the person with dementia or Dementia in this thesis I am speaking about the men and women who have been diagnosed with the disease. They are not the disease. They are, as Kitwood says, the “PERSON-with-dementia”.

### **2.5.2 A postmodern paradigm: The person with dementia and personhood**

The concept of personhood, as theory, is strongly embedded in psychology, social psychology, philosophy and dementia care. Understandings of personhood are culturally and philosophically influenced. Traditionally there has been a focus on biomedical and neuropathological factors which affect the person with dementia. There is also recognition of the range of psychosocial social factors which affect the way a person is perceived by others and the way they see themselves.

Defining personhood is dependent not only on the theories and paradigms within which the term personhood is being used, but it is also influenced through the values and beliefs of the user of that term. The practice of person-centred care, in health care and health sciences, is founded on notions of knowing the person and developing relationships with that person. But, what does it mean to really ‘know’ a person, especially as the person with dementia experiences difficulties in communication or others have difficulty in understanding what the person is wanting to communicate. There are challenges that need to be understood in order to know a person, relate to them as human beings who continue to change and apply this knowledge to provide person-centred practice.

Both Cooley and Mead took the view that our sense of self is derived from our ability to see ourselves through other's eyes in our interactions with each other. But Mead's account additionally gives the person the power to reflect upon such perceptions and to have a hand in

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<sup>187</sup> Kitwood, *Dementia Reconsidered: The Person Comes First*.

<sup>188</sup> Misztal, *Theories of Social Remembering*, 133.

<sup>189</sup> Kitwood, *Dementia Reconsidered: The Person Comes First*, 7.

the development of our own self-concept, enabling us to be more than simply the unwitting products of others' perceptions.<sup>190</sup>

These theories of personhood are part of a paradigm and worldview which emphasises the relational nature of identity and personhood; which are both constructed and perceived in relationship to other people. Importantly, it is the values and beliefs reflected in relationships with others which also influence the way we see ourselves. Harré describes personhood as a state of being which is mutable; it is ever changing, temporal, contextual and relational and yet human beings struggle to find the 'unity of self'.<sup>191</sup> He describes personhood in relation to a person's 'sense of self'.

[Personhood] is to have a sense of one's point of view, at any moment a location in space from which one perceives and acts upon the world, including that part that lies within one's own skin... 'a sense of self' is also used for the sense one has of oneself as possessing a unique set of attributes which, though they change nevertheless remain as a whole distinctive of just the one person. These attributes include one's beliefs about one's attributes. 'The self', in this sense is not an entity either. It is the collected attributes of a person. The word 'self' has also been used for the impression of his or her personal characteristics that one person makes on another.<sup>192</sup>

Stanghellini and Rosfort define personhood as "the fragile core of an emotional dialectic of selfhood and otherness". These authors assume that there is an inseparable relationship between personhood and emotions.<sup>193</sup> "Many emotions can exist only in the reciprocal exchanges of a social encounter."<sup>194</sup> And, as with the term personhood, understandings and definitions of emotions are also paradigmatic and dependent on the disciplinary contexts of their definition and use.<sup>195</sup> According to Harré in these social encounters we respond to what he calls local moral orders; that is the "local system of rights, duties and obligations, within which both public and private acts are done".<sup>196</sup> These contexts, which are continuously shifting, influence a person's experience of and behaviour within that context, and individuals have a tacit if not explicit understanding of their own rights to claim authority of remembering.<sup>197</sup>

Earlier in this chapter I introduced Descartes Cartesian dualism and the role this division of mind and body has in relation to the medical model and perceptions of the person with dementia. This dualism was embedded in the modernist tradition in which there was an objective outer world with a subjective inner world and this is still a powerful influence in

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<sup>190</sup> Burr, *The Person in Social Psychology*, 102.

<sup>191</sup> Harré, *The Singular Self: An Introduction to the Psychology of Personhood*, 2.

<sup>192</sup> *Ibid.*, 4.

<sup>193</sup> G. Stanghellini and R. Rosfort, *Emotions and Personhood: Exploring Fragility – Making Sense of Vulnerability* (Oxford: Oxford University Press, 2013), 2.

<sup>194</sup> R. Harré, ed., *The Social Construction of Emotions* (Oxford: Basil Blackwell, 1986), 147.

<sup>195</sup> Harré, *The Singular Self: An Introduction to the Psychology of Personhood*.

<sup>196</sup> Harré, *The Social Construction of Emotions*, 6.

<sup>197</sup> R. Harré and L. van Langenhove, "The Dynamics of Social Episodes," in *Positioning Theory: Moral Contexts of International Action*, ed. R. Harré and L. Van Langenhove (Oxford: Blackwell Publishers, 1999), 1.

scientific research.<sup>198</sup> These concepts underpin paradigms and disciplines from within which the world has been studied and new knowledge created. While modernist assumptions emphasised “the individual mind, an objectively knowable world, and language as the carrier of truth...the texts of postmodernism find the concept of individual rationality deeply problematic, if not oppressive in its function”.<sup>199</sup>

The postmodern is commensurate with the constructivist era in which personhood has been described as a paradigm; the “central assumption is that each person is a meaning-maker and an originating source of action”.<sup>200</sup> The postmodern/constructivist era emphasises

the creation, rather than the discovery, of personal and social realities...[it] stresses the viability, as opposed to validity, of knowledge claims. It also pays special attention to epistemological issues. Investigators and theorists become concerned with the how people know, as well as what they know...postmodernism/constructivism highlights human participation in the construction of knowledge.<sup>201</sup>

The initial diagnosis of dementia triggers a chain of events that can potentially alter a person's world before the symptoms do. Erving Goffman describes the stigma associated with being different. It is the anticipated differences which pose powerful changes in social interactions and shared attitudes.<sup>202</sup> The nature of dementia can result in a type of collateral discrimination where decision-making is perceived to be impaired and the person with the disease is ‘relieved’, to a smaller or greater degree, of the opportunities to voice their opinion regarding their own wellbeing.

Academic literature describes how people diagnosed with dementia are increasingly demanding to participate in research that is about them. They do not want to be excluded from research that relates to what is happening to them. They want to be heard. They want to express their opinions and describe their own experiences. They also want to help others who are or might someday be in a similar position. People with dementia have described the challenges they face not only in living with the disease but also in advocating for themselves in research.<sup>203</sup>

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<sup>198</sup> K. J. Gergen, “Psychological Science in a Postmodern Context,” *American Psychologist* 56, no. 10 (2001): 803–13, doi:10.1037/0003-066X.56.10.803.

<sup>199</sup> *Ibid.*, 59.

<sup>200</sup> R. Harré, “The Explanation of Social Behaviour,” *This Week's Citation Classic, Oxford, England* 28, no. July 13 (1987), <http://garfield.library.upenn.edu/classics1987/A1987H917200001.pdf>, as cited in Kitwood, *Dementia Reconsidered: The Person Comes First*, 15. This is an exemplar of alternative approaches to personhood in psychology. Kitwood draws on the work of social psychologist Harré (with a background of philosophy/social psychology) who describes personhood as a paradigm.

<sup>201</sup> Sexton, “Constructivist Thinking within the History of Ideas: The Challenge of a New Paradigm”, as cited in J. D. Raskin, “Constructivism in Psychology: Personal Construct Psychology, Radical Constructivism, and Social Constructionism,” *American Communication Journal* 5, no. 3 (Spring 2002), <https://ac-journal.org/journal/vol5/iss3/special/raskin.pdf>.

<sup>202</sup> E. Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York: Simon & Schuster, 1986), 3.

<sup>203</sup> F. E. Pison-Young et al., “I’m Not All Gone, I Can Still Speak: The Experiences of Younger People with Dementia. An Action Research Study,” *Dementia* 11, no. 5 (September 1, 2012): 597–616, doi:10.1177/1471301211421087; S. R. Sabat, “Epistemological Issues in the Study of Insight in People with Alzheimer’s Disease,” *Dementia* 1, no. 3 (November 1, 2002): 279–93, doi:10.1177/147130120200100302;

When I die nothing will be left except someone else's memory of me. Only these words of mine will remain to shred my life into moments I now quickly forget.<sup>204</sup>

This statement attests to the importance of not only how we remember and forget but how we are remembered and known by others. These are the words of Thomas DeBaggio who at the age of 57 was diagnosed with Alzheimer's disease. Thomas embarked on a journey in which he struggled with both the diagnosis and his sense of self in this lifetime. He decided to chronicle his experience of Alzheimer's disease. Thomas was not alone but one of the many hundreds of thousands of people who suffer from Alzheimer's disease globally. Alzheimer's disease is the most common cause of dementia. It has no cure. It is a terminal illness which is feared for its effect on memory loss but affects the whole body. It is not a normal ageing process and is diagnosed in people as young as in their twenties.

Thomas had for a brief time been a journalist though he did not fit the more right-wing ideology of the news services he worked for. After his diagnosis he turned his writing skills and that knowledge of the impending into a cause, a way of providing a voice and insight from within the experience of Alzheimer's disease.<sup>205</sup> Medical and community support is often focused first on the needs of the carer. Though this focus has shifted due to the activity of consumer groups, there is still much stigma associated with disease that affects memory and the community's perception of loss of ability to make informed decisions. The notion of advocacy depends on the perceptions, values and beliefs of those you speak to.<sup>206</sup>

After her diagnosis and in retrospect, Elaine Robinson was able to say that she may have had symptoms of Alzheimer's disease since she was 42 years old.

It doesn't follow that as soon as you are diagnosed you immediately become incapable of communicating. Many of us may have many years of good quality of life in front of us in which we can still be productive and make a valuable contribution to Alzheimer's research. What a hugely missed opportunity it would be if people with Alzheimer's were excluded from the very things that could be used to gain a fuller understanding of their disease. It would be simply denying us the chance to fill the gaps that no one else can. I realise that a cure for Alzheimer's disease may still be a long way off. I also know that the research I have taken part in so far will not benefit me personally, but taking part in it has lifted my morale, and I'm sure anyone else who has done the same will agree. To know that there are many dedicated people out there, who are willing to take the time and visit

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H. Bartlett and W. Martin, "Ethical Issues in Dementia Care Research," in *The Perspectives of People With Dementia: Research Methods and Motivations*, ed. H. Wilkinson (London: Jessica Kingsley Publishers, 2002), 47–61; M. Goldsmith, *Hearing the Voice of People with Dementia: Opportunities and Obstacles* (London: Jessica Kingsley Publishers, 1996); J. McKillop and H. Wilkinson, "Make It Easy on Yourself!," *Dementia* 3, no. 2 (June 1, 2004): 117–25, doi:10.1177/1471301204042332.

<sup>204</sup> DeBaggio, *Losing My Mind: An Intimate Look at Life with Alzheimer's*, 19.

<sup>205</sup> DeBaggio, *Losing My Mind: An Intimate Look at Life with Alzheimer's*.

<sup>206</sup> I attended the Alzheimer's Australia Conference in 2011 in which organisers attempted to break down some of the silence regarding what it is like to have Alzheimer's disease particularly for those affected at a much younger age. Speakers and keynote presenters included people diagnosed in their thirties.

us in our own familiar surroundings to listen and record our opinions, makes all the difference.<sup>207</sup>

There are many reasons why people with dementia want to be involved in research that is about them. The people cited so far in this section recognise that their perspectives are being omitted from the research due to the way they are perceived by others. Participating in research would create new knowledge built on the first person experience of dementia while challenging the perceptions of others and the assumptions they make. These reasons are salient drivers in considering how a problem space in research is conceptualised and understood. Importantly, the words of these people with dementia are a warrant to design a study around their needs as the primary partners in research.

Understanding the situated context is about understanding what is happening for an individual from their unique perspectives. In preparing the material in this section, I was aiming to inform myself about the theory of working with people with dementia and to understand the impact of dementia in their lives. In Chapter 3 I draw the sensitisation achieved in relation to this through and into the research design.

## **2.6 *Participating In The Archival Turn: The Emergent State of Research***

The archival turn is an ongoing process reflecting postmodern paradigmatic shifts in the archival community. As someone researching the co-creation of person-centred records in the context of dementia it is important to locate my work amongst other emergent studies and theories currently occurring within archival science. Research and writing in the postmodern era drawing on participatory epistemology in the creation of records and archives are proliferating. In the following paragraphs I highlight several of these studies.

The worldviews of the people in these communities are not only changed by new ways of thinking but continue to be challenged by new spaces for research and practice. It is pertinent to acknowledge that I am part of a broader community of archival researchers who are working in emergent and complementary areas of study. The results of these studies are being published through doctoral work and in special edition journals. These studies address new archival knowledge particularly with regard to how we understand records and the human relationship to recordkeeping.

Recent works by Gilliland, Caswell, Lee and Cifor address new aspects of theory regarding the affective nature of records. These works emerge from diverse archival contexts. Their research contexts have a strong focus on the recordkeeping implications for agency and human rights. Gilliland is currently undertaking ethnographic research which is focused on

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<sup>207</sup> Robinson, “Should People with Alzheimer’s Disease Take Part in Research?” 104.

peoples' experiences of "records and recordkeeping during and since the Yugoslav Wars."<sup>208</sup> Caswell is researching and writing about in-depth studies into South Asian archives to understand how records are both agents of silence and for witnessing.<sup>209</sup> Lee has explored how queered and transgendered archives "take shape and simultaneously reshape the creators of the records in the course of (re)assembling and (re)accessing meaningful material lived histories."<sup>210</sup> Cifor argues the need to understand theories of affect in relation to records and archives; especially with respect to *how* archival work and inherent relationships are mediated by affect.<sup>211</sup>

Several of these researchers raise issues associated with the challenges of how archivists work with records, existing, missing or never created.<sup>212</sup> Additionally it is recognised "that signs carry meaning, their work often neglects the ways in which these signs are imbued with affective intensities."<sup>213</sup>

Throughout the course of my thesis work I have had the opportunity to attend archival conferences and institutes in which I have had opportunities to speak and share with contemporary archival theorists. I have presented several papers and conducted workshops associated with my research. These include the following presentations which were given at the Archival Education and Research Institute:

- The Storyline Project: Determining a therapeutic use for the personal archive. (2010)
- New contexts for the archival profession: creating and repurposing the personal record for therapeutic uses. (2011)
- Review of Extensive Interdisciplinary Stakeholder Consultation Throughout the Storyline Project. (2012)

The presentations have generated helpful dialogue and I consider that my work fits this emergent area of scholarship.

Gilliland et al. call for the archival community to address the recordkeeping needs of marginalised communities. This type of research creates challenges in working across disciplines, frameworks and with concepts from outside archival science.<sup>214</sup> This shift in thinking and scope for archival research and education reflects changing paradigmatic boundaries for members of the archival community. In this way the contemporary archival

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<sup>208</sup> A. J. Gilliland, "Moving Past: Probing the Agency and Affect of Recordkeeping in Individual and Community Lives in Post-Conflict Croatia," *Archival Science* 14, no. 3–4 (October 2014): 249, doi:10.1007/s10502-014-9231-3.

<sup>209</sup> M. Caswell, *Archiving the Unspeakable: Silence, Memory, and the Photographic Record in Cambodia* (Madison, WI: University of Wisconsin Press, 2014), <https://books.google.com.au/books?id=eWziAgAAQBAJ>.

<sup>210</sup> J. A. Lee, "Be/longing in the Archival Body: Eros and the 'Endearing' Value of Material Lives," *Archival Science* 16, no. 1 (2016): 34, doi:10.1007/s10502-016-9264-x.

<sup>211</sup> M. Cifor, "Affecting Relations: Introducing Affect Theory to Archival Discourse," *Archival Science* 16, no. 1 (November 2, 2015): 7–31, doi:10.1007/s10502-015-9261-5.

<sup>212</sup> A. J. Gilliland and M. Caswell, "Records and Their Imaginaries: Imagining the Impossible, Making Possible the Imagined," *Archival Science* 16, no. 1 (2015): 53–75, doi:10.1007/s10502-015-9259-z; Cifor, "Affecting Relations."

<sup>213</sup> Cifor, "Affecting Relations," 12.

<sup>214</sup> Gilliland et al., "Pluralizing the Archival Paradigm through Education."

community is both able to influence change through problem solving in new contexts and be changed by their actions.

The empirical research reported in this thesis is a contemporary of the work described in this section; where archival scholars are deepening archival learning regarding the affective nature of records while introducing new theories and bodies of knowledge to archival discourse.<sup>215</sup> Importantly, this in-depth research provides opportunities to make explicit the epistemologies; “the process of thinking. The relationship between what we know and what we see”<sup>216</sup> which underpin *how* we represent, experience, understand and co-create the person-centred record.

## 2.7 Conclusion

Archival communities are exploring new ways of seeing and understanding archival and recordkeeping concepts.<sup>217</sup> Within the Australian recordkeeping and archival context, postmodern and continuum thinking is also encouraging the development of models and theories, which lend themselves to addressing new research problems in archives and recordkeeping. This surge of interest within archival science converges with increasing awareness of more global concerns regarding; human rights, ethics and evolving characteristics of research methodologies.

This study is informed by postmodernism, a participatory epistemology and personhood in developing a holistic approach to working with people with dementia and co-creating records. Perspectives of records are explored through the eyes of participants in the research. The challenge of co-creating records involves a complexity which requires its own frame of reference in terms of phenomena and methodologies for research – in theory and in practice.

The task of developing theoretical sensitivity as part of the grounded theory process has been achieved by working through:

- Contemporary postmodern disciplinary theories in archival science (records continuum thinking, structuration theory, personal recordkeeping)
- Records in relation to supporting consideration and conceptualisation about personal records: memories, meanings and pluralities
- The situated contexts and personhood needs of people with dementia.

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<sup>215</sup> “In November 2014, a symposium on Affect and the Archive was held at the University of California, Los Angeles.” This event resulted in a special edition of the journal *Archival Science*, published in late 2015, marking the importance of affect and emotions in the study of records and archives. M. Cifor and A. J. Gilliland, “Affect and the Archive, Archives and Their Affects: An Introduction to the Special Issue,” *Archival Science* 16, no. 1 (November 20, 2015): 1–6, doi:10.1007/s10502-015-9263-3.

<sup>216</sup> Denzin and Lincoln, “Paradigms and Perspectives,” 103.

<sup>217</sup> T. Nesmith, “Reopening Archives: Bringing New Contextualities into Archival Theory and Practice,” *Archivaria* 60 (2006): 259.

## 3 Research Methodology: In Theory and Practice

### 3.1 *Introduction*

In Chapters 1 and 2, I described the broader settings within which this research is situated; the context of the person with early stage dementia and the significance of records in supporting memory, identity and personhood within archival and health settings. I explained my position with respect to philosophical and theoretical concerns regarding the person with dementia.

In this chapter I discuss the approach I used to generate a second generation grounded theory. This approach is my interpretation of the methodology in theory and how it played out in practice. I introduce second generation grounded theory as a methodology synergistic with the family of theories relevant to this research (described in Chapter 2) and the research context.

This chapter is presented in five main parts.

- Section 3.2: An introduction to the overarching approach to this research with regard to researcher intent and principles, within a postmodern paradigm.
- Section 3.3: A discussion of the approach, tenets and design of this second generation grounded theory; suited to participatory epistemology and iterative approaches to working with participants in research and their data.
- Section 3.4: Articulates the methods and techniques implemented as part of the overarching approach explained in Section 3.3. The methods and techniques which supported this approach are described in terms of how they facilitated understanding complex and multiple perspectives of participant voice and meaning. I explain how the theory and philosophical approach has translated into innovation in practices for archival research.
- Section 3.5: Addresses fundamental research activities which supported the way this study was designed and conducted.
- Section 3.6: Provides an overview of the outcomes of the research methods and techniques as a framework for this second generation grounded theory research.

#### 3.1.1 A prelude

Before addressing these sections I would like to share a reflective piece written as a prelude. For me the piece assisted in understanding the postmodern perspectives which underpin the design of this research. Rosenau wrote:

Post-modern social scientists support a re-focusing on what has been taken for granted, what has been neglected, regions of resistance, the forgotten, the irrational, the



insignificant, the repressed, the borderline, the classical, the sacred, the traditional, the eccentric, the sublimated, the subjugated, the rejected, the non-essential, the marginal, the peripheral, the excluded, the tenuous, the silenced, the accidental, the dispersed, the disqualified, the deferred, the disjointed... Post-modernists, defining everything as a text, seek to “**locate**” meaning rather than to “discover” it. They **avoid judgment**, and the most sophisticated among them **never “advocate” or “reject,”** but speak rather of **being “concerned with” a topic or “interested in” something.** They **offer “readings”** not “observations,” “**interpretations**” not “findings; they “**muse**” about **one thing or another.** They never test because testing requires “evidence,” a meaningless concept within a post-modern frame of reference.

These different terminologies incorporate adversarial views of the world. Learning these words and understanding their usage involve more than new ways of communicating; such intellectual activity requires **re-setting the code** one normally employs and social science analysis, **turning around one’s thought processes”**.<sup>218</sup> (emphases added)

These postmodernism and post concepts juxtapose each other.

[Postmodernists] offer **indeterminacy** rather than determinism, **diversity** rather than unity, difference rather than synthesis, **complexity** rather than simplification. They look to the **unique** rather than to the general, to **intertextual relations** rather than causality, and to the **unrepeatable** rather than the re-occurring, the habitual, or the routine. Within a post-modern perspective social science becomes a more subjective and humble enterprise as truth gives way to **tentativeness.** **Confidence in emotion** replaces efforts at impartial observation. **Relativism is preferred** to objectivity, **fragmentation** to totalization.<sup>219</sup> (emphases added)

These excerpts are salient in how they denote the complexities of working within postmodern paradigms. Rosenau provokes readers to engage in their contexts; to look beyond what they know, their own assumptions, and the assumptions of others; to explore what lies between the gaps of our perceptions. To seek that we pass over without ever seeing. To question how we know. Where do we begin?

This chapter is about beginnings: I am reviewing what is committed to the past but being constructed in the present. This is my experience of the research and interpreting theory into practice. As a researcher I designed a methodology and processes which allowed me to live out and represent postmodern sensibilities in order to conceptualise what I heard, saw and experienced.

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<sup>218</sup> P. M. Rosenau, *Post-Modernism and the Social Sciences: Insights, Inroads, and Intrusions* (Princeton, NJ: Princeton University Press, 1991), 8.

<sup>219</sup> *Ibid.*

### **3.2 Overarching Approach to Archival Research: Researcher Intent, Principles, Values and Beliefs**

This study was informed by what I describe as a set of overarching principles which have guided me in establishing key research activities. These principles were derived from my experience, values and beliefs in relation to the paradigms and theories drawn on in the research which were explored through the literature in Chapter 2. These principles highlight the need to:

1. Take a consultative approach to people and knowledge
  - Reflecting the postmodern paradigm and participatory epistemology.
  - Developing and sharing knowledge was part of a consultative and often collaborative process. This type of learning occurred through engagement with stakeholders and learning in a range of related contexts to create a broader and more informed picture of how the research and the contribution to knowledge was situated.
2. Design inclusive and person-centred research
  - Reflecting personhood as a philosophical approach to working with people and respecting their ability to speak for themselves.
  - It was important to address the power inequalities between researcher and people with dementia as participants. In practice this meant creating person-centred research in which I as the researcher listened to the views of the participants, assumed the integrity of their voice and did not reinforce the stigma so often associated with dementia.
3. Understand the roles we play in constructing realities and conducting ethical research
  - Reflecting the social constructionist lens and plurality of perspectives in co-creating records.
  - As the researcher I am a conscious actor. Doing research is a reflexive process which challenges me as the researcher to see and work with the 'complexity of the parts'. Doing ethical research demands that complexity is not diminished or simplified but rather acknowledged for what it is.
4. Experience research as a journey not just the destination
  - Reflexivity was a core activity in developing processes and practice which facilitate hearing the voices of participants and exploring meaning as it was constructed.
  - In order to learn from what I have done I analysed research processes as well as the data and their relationships throughout the research. Models, maps and metaphors were tools for analysing and visualising multiple perspectives and levels of complexity.

These four principles identified above represent intent in how I designed the research and the supporting activities. The research activities began in the early stages of scoping the research and writing the research proposal. The range of activities continued to develop and mature throughout the phases of the research to influence me as the researcher as well as guide dimensions of the research.

In addition, it is important to state that these principles were informed by postmodern assumptions and ethical responsibilities associated with postmodern methodologies. In the following paragraphs I highlight key points with respect to these assumptions.

There is debate across the academy, professional schools and other sites of knowledge production, about just where we are in the context of the postmodern turn.<sup>220</sup> The postmodern researcher contests older positions, “renounces the search for necessity, certainty and universality, content with claims for local and provisional knowledge, with interpreting meanings rather than legislating truths or values.”<sup>221</sup> The postmodern theorist prefers to “abandon overarching paradigms and theoretical methodological metasystems” in order to position themselves within complexity by studying in detail the smaller, even fragmented parcels of knowledge in order to learn about the “the multiple levels of social reality”.<sup>222</sup> Instead of posing master narratives and vocabularies, empirical realities are viewed as stories and narratives.<sup>223</sup> This thinking is consistent with the practices adopted in this research with respect to researcher intent, principles, values and beliefs.

These responsibilities in postmodern research also generate views on the importance of ethics and being an ethical researcher. Research ethics is a branch of “applied (or practical) ethics which studies the ethical problems, dilemmas, and issues that arise in the conduct of research.”<sup>224</sup> Ethics is described by scholars as being “concerned with...questions about duty, honour, integrity, virtue, justice, and the good life,”<sup>225</sup> and about being responsible, a good citizen, objective, honest, accurate, and efficient.<sup>226</sup> Ethics in postmodern times is less about being right or wrong and more about the process of making choices from other possible choices.

Postmodern ethics according to Bauman is “more than anything else – a state of mind” which opens up people and society to complexity and the unknown. ‘Understanding began to be recognised as the ‘mode of being before defining the mode of knowing.’” It is an existence of uncertainty and subjectivity in which the ethical responsibilities of individual agents increase and formal guidance diminishes.<sup>227</sup> It is a way of perceiving the world and our place in it as active agents of self-reflective knowing able to critique the phenomena of tradition, power and control. This does not mean that we live in a world void of frameworks but rather it

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<sup>220</sup> Clarke, “Situational Analyses,” xxiv.

<sup>221</sup> Kellner, “Zygmunt Bauman’s Postmodern Turn,” 76.

<sup>222</sup> Borer, Silverman as cited in Borer and Fontana, “Postmodern Trends: Expanding the Horizons of Interviewing Practices and Epistemologies.”

<sup>223</sup> Lyotard, *The Postmodern Condition: A Report on Knowledge*; Gubrium and Holstein, *The New Language of Qualitative Method*.

<sup>224</sup> A. E. Shamoo and D. B. Resnik, *Responsible Conduct of Research*, 3rd ed. (Oxford: Oxford University Press, USA, 2009), 15, <http://books.google.com.au/books?id=dP7oKntCUUUC>.

<sup>225</sup> Ibid., 13.

<sup>226</sup> N. H. Steneck, *ORI Introduction to the Responsible Conduct of Research*, rev. ed. (Washington, DC: Department of Health & Human Services USA, 2007), xi, [https://books.google.co.in/books?id=4ngu1a7tNhkC&printsec=frontcover&dq=Introduction+to+the+Responsible+Conduct+of+Research&hl=en&sa=X&ved=0ahUKEwiVwpCp\\_bDLAhVEJJQKHU\\_HAc0Q6AEIHDAA#v=onepage&q=Introduction%20to%20the%20Responsible%20Conduct%20of%20Research&f=false](https://books.google.co.in/books?id=4ngu1a7tNhkC&printsec=frontcover&dq=Introduction+to+the+Responsible+Conduct+of+Research&hl=en&sa=X&ved=0ahUKEwiVwpCp_bDLAhVEJJQKHU_HAc0Q6AEIHDAA#v=onepage&q=Introduction%20to%20the%20Responsible%20Conduct%20of%20Research&f=false).

<sup>227</sup> Z. Bauman, *Intimations of Postmodernity* (London: Routledge, 1992), vii.

reinforces the need to try and understand the plurality of perspectives and experiences which co-exist in the face of modernity.

In this research, I have adopted the ethical stance of seeking to understand the plurality of participants' perspectives, and their experiences, and bring these to light through co-creating person-centred records. This is also consistent with the values of social constructionism which assumes that though we all share in the same world, the way that world is understood is unique to individuals and meaning is constructed through social relationships.<sup>228</sup>

Considering the philosophical underpinnings and associated values and beliefs, both personal and professional I have sought to reveal much about the premises about my research thinking and practices. Ethically and practically I have sought to describe and explicate my thinking and actions as the research was conducted. "The political and personal perspectives of researchers inform the intentions we have for the research."<sup>229</sup> Together these have formed a sustainable approach to being an ethical researcher in a postmodern project. In addition, they form an important part of methodological wayfinding which is discussed in Section 3.3.1.

### **3.3 *In Theory: Approaching Second Generation Grounded Theory***

In the previous section I introduced the overarching principles which guided me in this research. In this section I report on the theoretical aspects of second generation grounded theory which informed the design of this research. This is presented in four sub-sections. These are:

- Methodological wayfinding
- Proposing a second generation grounded theory
- Tenets of second generation grounded theory
- The fit of second generation theory with records continuum thinking.

#### **3.3.1 Methodological wayfinding: A responsive approach to the application of second generation grounded theory**

Wayfinding is the process of determining and following a path or route between an origin and a destination, that may be known or unknown. It is a purposive, directed, and motivated activity.<sup>230</sup>

This definition of wayfinding bears a striking resemblance to how I would describe my experience of designing and practising in this second generation grounded theory. Methods and techniques were used incrementally to address methodological and technical challenges as

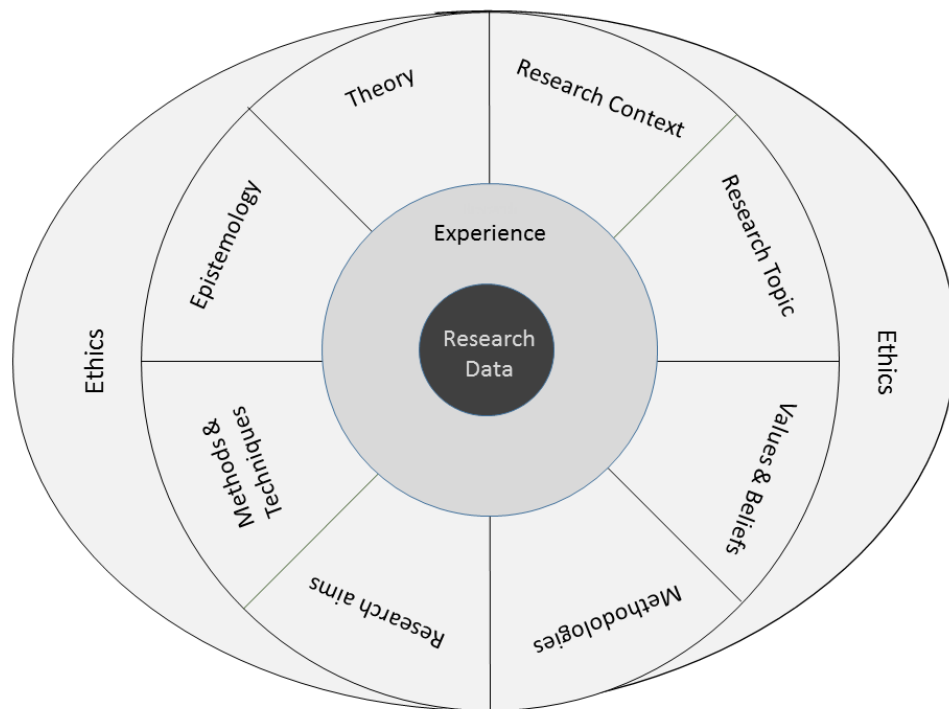
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<sup>228</sup> M. Gergen and K. J. Gergen, *Social Construction: Entering the Dialogue*, (Chagrin Falls, OH: Taos Institute Publications, 2004), Kindle Location 97. Kindle Edition.

<sup>229</sup> Gillies and Aldred, "The Ethics of Intention: Research as a Political Tool," 1.

<sup>230</sup> R. G. Golledge, ed., *Wayfinding Behavior: Cognitive Mapping and Other Spatial Processes* (Baltimore, MD: Johns Hopkins University Press, 1999), 7.

they arose. I was in a continuous process of navigating dimensions of the research (as illustrated in Figure 2) across data, themes, theory, researcher, participants and stakeholders, as well as practitioners and experts in a range of disciplines, to understand the phenomena and develop theory and ethical practice. As the researcher I became engaged in a pivotal point of discourse between the people, the literature and the theory in a world of ‘many realities’.



**Figure 2 Methodological wayfinding**

In light of this research reality, I coined the term *methodological wayfinding* to describe methodology as a journey and evolving through situated contexts, the iterative process of interaction with theory, practice and research product. In implementing a second generation grounded theory to this study, it was key concepts associated with wayfinding which I identified with so strongly. Research that is iterative and reflexive is not prescriptive but rather acknowledges that knowledge creation is guided by reflexive and iterative practices and immersion in rich and sometimes diverse research contexts.

The emergent data lead to knowledge which was outside my own areas of expertise. This type of research activity involved identifying what keywords or themes ‘might’ be significant in the data and exploring the literature and theory to establish their salience to the research. This step also provided important thematic clues and the adaption of techniques to progress interviews and data collection. For me, it entailed many hours pursuing keywords and phenomena that have emerged from the discussions, interviews and data.

As a qualitative researcher I found myself working as what has been described in literature as an interpretive bricoleur.<sup>231</sup> The term bricoleur originates from the French and describes “handyman or handywoman who makes use of the tools available to complete a task”.<sup>232</sup> The term interpretive bricoleur has been adopted to convey a characteristic working style in which the researchers themselves are adept at bringing together a range of knowledge, skills and tools from varying disciplines to the context being studied. The work is intentional and conscious of the processes which influence and inform presentation and representation to find new ways of knowing.<sup>233</sup>

The “bricoleur’s method is an emergent construction” in response to an individual context.<sup>234</sup> The concept of bricoleur has been adopted amongst qualitative researchers in relation to how interpretive practices converge to “make(s) the world visible in a different way.” This ability to problem solve and improvise is critical when undertaking applied research in sensitive social contexts. This is particularly relevant when problem solving and addressing new problems in research requires innovation. If the necessary tools are not at hand then new techniques or tools are orchestrated or created.<sup>235</sup>

The interpretive bricoleur seeks to make sense of the world through “a pieced-together set of representations that are fitted to the specifics of a complex situation”.<sup>236</sup> “The solution (bricolage) which is the result of the bricoleur’s method is an [emergent] construction.”<sup>237</sup> de Certeau describes bricolage as “the poetic ways of making do”.<sup>238</sup> Attention to the “aesthetics of representation that goes beyond the pragmatic or the practical”.<sup>239</sup> If wayfinding describes the journey, then the interpretive bricoleur brings the expertise and adaptive approach to researcher practice.

Methodological wayfinding reflects an ongoing and reflexive process, for determining and understanding the relationships that can be constructed between second generation grounded theory and archival theory, in a way that is sensitive to participants involved in the research. It is in these relationships that we can see how the postmodern principles espoused by these generations of archival theory and grounded theory guide the method of research and interpretations of the phenomena being studied.

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<sup>231</sup> Denzin and Lincoln, *The Handbook of Qualitative Research*, 4.

<sup>232</sup> J. L. Kincheloe, “Describing the Bricolage: Conceptualizing a New Rigor in Qualitative Research,” *Qualitative Inquiry*, no. 7 (2001): 680, doi:10.1177/107780040100700601.

<sup>233</sup> N. K. Denzin and Y. S. Lincoln, *The SAGE Handbook of Qualitative Research*, (Thousand Oaks, CA: SAGE Publications, 2011), 681. Kindle Edition.

<sup>234</sup> D. Weinstein and M. A. Weinstein, “Georg Simmel: Sociological Flaneur Bricoleur,” *Theory, Culture & Society* 8, no. 3 (August 1, 1991): 161, doi:10.1177/026327691008003011.

<sup>235</sup> Denzin and Lincoln, *The Handbook of Qualitative Research*, 3–4.

<sup>236</sup> *Ibid.*, 4.

<sup>237</sup> Weinstein and Weinstein, “Georg Simmel.”

<sup>238</sup> M. de Certeau, *The Practice of Everyday Life* (Berkeley, CA: University of California Press, 2011), xv, [http://books.google.com.au/books?id=Csl\\_AAoUT8C](http://books.google.com.au/books?id=Csl_AAoUT8C).

<sup>239</sup> N. K. Denzin and Y. S. Lincoln, “Introduction: The Discipline and Practice of Qualitative Research,” in *The SAGE Handbook of Qualitative Research* (Thousand Oaks, CA: SAGE Publications, 2011), 4.

I understood where I was heading but in a world of many realities and perspectives I was ‘feeling’ my way when implementing methods and techniques to explore what Liamputtong describes as the “ambiguity and contextuality of meaning”.<sup>240</sup> Importantly, social construction occurs in all the dimensions of research. It is part of the researcher’s responsibility to understand the dynamism of creating knowledge especially when considering the participants’ perspectives.

A focus on the collection and analysis of data and the research context is core to the research process yet only a part of the broader context. There were conflicting beliefs regarding the place, effect and value of referring to existing literature, and I would add knowledge from other sources, (see Section 3.4.3 on stakeholder engagement) in grounded theory. As Urquhart explains the belief of not having any preconceived theoretical ideas is more about looking to see what emerges from the data rather than see what we may already ‘know’ and therefore expect to see.<sup>241</sup> Methodological wayfinding is a reflexive and responsive practice which reinforces ongoing learning and development of knowledge through a range of contexts.

### 3.3.2 Proposing a second generation grounded theory

It is generally recognised that there are two generations of grounded theory, possibly evolving into a third generation. When first generation grounded theorists Glaser and Strauss first published *The Discovery of Grounded Theory* in 1967, they were building on the work of the Chicago School of Sociology as well as advancing the standing of qualitative research methods which were struggling to gain recognition in a positivist research environment. Grounded theory, as a methodology, shifted the focus of research from testing existing theory to that of generating new theory from data.<sup>242</sup>

The classic form of grounded theory, as described by sociologists Glaser and Strauss, emerged from their research on dying hospital patients in 1965.<sup>243</sup> Grounded theory was defined as a strategy for the “discovery of theory from data – systematically obtained and analysed in social research”.<sup>244</sup> It was a response to the prevalence in research, on rigorous testing of extant theory. This was a paradigmatic shift to producing theory grounded in the data itself; where the aim was to generate new theory rather than force the data into existing theory.<sup>245</sup> As such grounded theory has contributed to methodological repertoires of a range of disciplines studying the social sciences studying new problem spaces.

Glaser and Strauss emphasised that “generating grounded theory was a way of arriving at theory suited to its supposed uses”. Rather than being positioned as a set of definitive or

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<sup>240</sup> P. Liamputtong, *Researching the Vulnerable: A Guide to Sensitive Research Methods* (Los Angeles, CA: SAGE, 2007), 15.

<sup>241</sup> Urquhart, *Grounded Theory for Qualitative Research: A Practical Guide*, 17.

<sup>242</sup> M. Birks and J. Mills, *Grounded Theory: A Practical Guide* (London: SAGE Publications, 2011), 2.

<sup>243</sup> B. G. Glaser and A. L. Strauss, *Awareness Of Dying* (London: Weidenfeld & Nicolson, 1967).

<sup>244</sup> B. G. Glaser and A. L. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (New York: AldineTransaction, 1967), 1.

<sup>245</sup> Ibid.

formulaic procedures classic grounded theory was a strategy for handling data so that the theories would ‘fit’ the research situation and ‘work’ when used. And, because the theories were so inextricably linked to the data they should also exhibit enduring qualities.<sup>246</sup>

“A grounded theory is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory stand in reciprocal relationship with each other. One does not begin with a theory then prove it. Rather, one begins with an area and what is relevant to that area is allowed to emerge.”<sup>247</sup>

It was through extensive teaching and mentoring that Glaser and Strauss informed a new generation of researchers who, through their own work, have in turn influenced further generations.<sup>248</sup> Both the methodology and the researchers were particularly influenced by work “focused on the illness experience and associated phenomena (such as caregiving)”<sup>249</sup> The genealogy of grounded theory demonstrates how by the 1990s classic grounded theory was already cultivated into two strands of grounded theory by their founders Glaser and Strauss.<sup>250</sup> The two strands of grounded theory are attributed to a dispute between Glaser and Strauss. Glaser was concerned about prescriptive coding process being promoted by Strauss and Corbin. For Glaser, prescriptive coding practices risked forcing data to do or be something through a particular paradigm rather than letting the codes and theory emerge from the research context and data.<sup>251</sup>

Divergent paradigms were at the core of these evolving streams in grounded theory. The dynamic nature of the methodology is reflected in the lineage of grounded theory which has seen those students who initially learned from and were mentored by Glaser and Strauss, continue to contribute to the methodology and its evolution with new and distinctive methods. This evolution of grounded theory has seen the development of what has become known as a second generation of grounded theory.

In an ontological and epistemological shift, second generation grounded theorists conceived quite differently to classic grounded theorists, regarding the world and their place in it. This shift in worldview has seen grounded theory develop into a methodology which seeks to understand rather than explain phenomena. Charmaz asserts that this type of theory “assumes multiple realities; indeterminacy; facts and values as inextricably linked; truth as provisional; and social life as processual.”<sup>252</sup> In conducting interpretive research “we interpret our participants meanings and actions and they interpret ours.”<sup>253</sup> The interaction between

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<sup>246</sup> Ibid., 3.

<sup>247</sup> A. Strauss and J. M. Corbin, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. (Thousand Oaks, CA: SAGE Publications, 1990), 23.

<sup>248</sup> J. M. Morse et al., *Developing Grounded Theory: The Second Generation* (Walnut Creek, CA: Left Coast Press, 2009).

<sup>249</sup> Ibid., 13.

<sup>250</sup> Ibid., 14.

<sup>251</sup> Strauss and Corbin, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*.

<sup>252</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 126.

<sup>253</sup> Ibid., 127.



researcher, participants, the data and social context, demand that the researcher be as close as possible to the inside experience, but also acknowledges that the phenomena are the individual's unique experiences.<sup>254</sup>

Two of the key proponents in this second generation of grounded theory are Kathy Charmaz, who studied with both Glaser and Strauss and developed constructivist grounded theory, and Adele Clarke who, after studying with Strauss developed the approach of Situational Analysis.<sup>255</sup> In contrast to classic grounded theory this second generation of grounded theorists embraced a constructivist approach to grounded theory which was highly contextual and influenced by interpretivist and postmodern frameworks.<sup>256</sup> Both Charmaz and Clarke, in particular, identified how the human experience is embedded in broader contexts. It is at this point that the 'differences and distinctions' between generations of grounded theory become visible.<sup>257</sup>

Constructivist grounded theory, with its focus on how and why meaning is constructed, "uses the methodological strategies developed by Glaser, the spokesperson for objectivist grounded theory, yet builds on the social constructionism inherent in Anselm Strauss's symbolic interactionist perspective."<sup>258</sup> In fitting with an interpretivist approach constructivism guides the underpinning questions in the research as it considers all social realities as being socially constructed. It asks how individuals within a particular context construct and act on their own reality.<sup>259</sup>

Through situational analysis, Clarke illustrates how she has taken grounded theory past the 'postmodern turn' to find new ways of focusing on and studying these differences. Clarke uses mapping and situational analysis as powerful methods for explicating the constructs of the material or nonhuman world as well as the human world. This is particularly relevant for archival research where records are studied as products of human activity. Clarke attributes her emphasis on a more open and fluid studying of social worlds, arenas and discourses to Strauss's "Chicago ecological bent" which translates into "ecological and cartographic metaphors".<sup>260</sup> Carey describes this as Strauss's own 'sociology of structuration'.<sup>261</sup>

These innovations in second generation grounded theory highlight a new methodological form for the study of human activities which is inherently reflexive and iterative in nature.

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<sup>254</sup> Ibid., 130.

<sup>255</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*; Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*.

<sup>256</sup> Morse et al., *Developing Grounded Theory: The Second Generation*.

<sup>257</sup> Clarke, "Situational Analysis"; Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*.

<sup>258</sup> K. Charmaz, "Grounded Theory Methods in Social Justice Research," in *The SAGE Handbook of Qualitative Research*, ed. N. K. Denzin and Y. S. Lincoln, 4th ed. (Thousand Oaks, CA: SAGE Publications, 2011), 365.

<sup>259</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 127; Patton, *Qualitative Research and Evaluation Methods*, 96.

<sup>260</sup> Clarke, "Situational Analyses."

<sup>261</sup> J. W. Carey, "Cultural Studies and Symbolic Interactionism; Notes in Critique and Tribute to Norman Denzin," *Studies in Symbolic Interaction* 25 (2002): 199–209. Strauss was working on this well before structuration theory was described by Giddens.

Multiple perspectives reverberate to elucidate the visible and the invisible in what is always part of something more complex. Charmaz describes second generation grounded theory as a “method for qualitative enquiry in which data collection and analysis reciprocally inform and shape each other through an emergent iterative process. The term, “grounded theory”, refers to this method and its product, a theory developed from successive conceptual analysis of data”.<sup>262</sup> Second generation grounded theory is a “particular way of thinking about data” which has evolved and continues to evolve in response to the varying contexts in which it is used.<sup>263</sup>

In second generation grounded theory the methods used for collection of data are not prescribed but dependent on what is most effective and appropriate for studying the phenomena in the context of the research. It is a systematic approach to enquiry which relies on reflexive and iterative practices to data collection and analysis. The researcher continues to interact with the data, observations and participant voices and to refine the analysis until completion of the study. Bowers in a dialogue with Morse and Clarke explains that working within second generation grounded theory means that the researcher must be comfortable “with a high level of ambiguity that comes with the method and the ‘false starts’ or changing directions – there are a lot of these, exploring different directions”. This is not wasted time but rather an important part of a process which reinforces the ongoing analytic work upon which grounded theory is founded.<sup>264</sup>

Second generation grounded theory is part of a grounded theory methodological continuum. Theorists such as Charmaz and Clarke have been influenced by constructivist and postmodern writings. Applying their knowledge into new contexts has contributed to the development of their own methods and processes as well as the traditions of classic grounded theory. Corbin is an interesting example of a traditional grounded theorist who in more recent years re-evaluated her own position whilst undertaking the (re)writing of the third edition of *Basics of Qualitative Research*. She explained quite candidly how her own perceptions of qualitative research have changed dramatically since she was first trained by Strauss in grounded theory. The field of qualitative research along with her own knowledge and experience have evolved and reflect the influences of contemporary philosophy and sociology and their effects on values, beliefs, attitudes, and knowledge. According to Corbin, methods are evolving to address methodological problems faced by researchers in the field.<sup>265</sup>

### 3.3.3 Tenets of second generation grounded theory: Constructivist and postmodern

In section 3.2 of this chapter I outlined researcher intent in relation to this second generation grounded theory as a methodology. The key tenets of second generation grounded theory

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<sup>262</sup> Charmaz, “Grounded Theory Methods in Social Justice Research,” 360.

<sup>263</sup> J. M. Morse et al., “Tussles, Tensions, and Resolutions,” in *Developing Grounded Theory: The Second Generation* (Walnut Creek, CA: Left Coast Press, 2009), 14.

<sup>264</sup> B. Bowers et al., “Dialogue: Doing ‘Grounded Theory,’” in *Developing Grounded Theory: The Second Generation* (Walnut Creek, CA: Left Coast Press, 2009), 21.

<sup>265</sup> J. Corbin and A. Strauss, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (Thousand Oaks, CA: SAGE Publications, 2008), vii.

highlight a shift in understanding how researchers interact with participants in a study. The constructivist and postmodern underpinnings highlight the way relationships between researcher, participant and research data are both inseparable and the product of their combined interactions.<sup>266</sup> Second generation grounded theorists argue that hearing and knowing the voice of participants requires methods and techniques, for working with data which “exposes more about the ‘nuances of...language and meanings’”.<sup>267</sup>

Interviews therefore become the ‘site for the construction of knowledge, [where] clearly the researcher and informant produce this knowledge together’ (Hand, 2003;17). In the construction of such knowledge, information generated needs to reveal depth, feeling and reflexive thought. This approach is representative of contemporary beliefs about grounded theory interviewing as a method of data generation. Interviews are not neutral, context-free tools; rather, they provide a site for interplay between two people that leads to data that is negotiated and contextual.<sup>268</sup>

The shared construction of knowledge places an emphasis on reflexive and interpretive practice for the second generation grounded theorist. What is it that constitutes the criteria for quality in constructivist research, where the conduct of the research as well as the outcomes, are so dependent on the qualities of the researcher?

Lincoln and Guba urge that “The quality (rigor) criteria for an inquiry cast in relativist ontological terms, in transactional/subjectivist epistemological terms, and in hermeneutic/dialectic terms must be appropriate to such a paradigmatic framework; they cannot be objectivist or foundational...Whatever criteria emerge, they must also reflect the moral, ethical, prudential aesthetic, and action commitments of constructivism”.<sup>269</sup>

The researcher is an integral part of the research. Adoption of a social constructionist lens infers that I as the researcher am always present. I am challenged to be mindful of positioning. As much as I am studying a particular context, I am also under scrutiny. Reflexivity is played out through the practice of negotiating and representing complex and plural perspectives.

Constructivist grounded theory has its foundation in relativism and an appreciation of the multiple truths and realities of subjectivism. Undertaking a constructivist enquiry requires the adoption of a position of mutuality between research and participant in the research process, which necessitates a rethinking of the grounded theorist’s traditional role of objective observer.<sup>270</sup>

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<sup>266</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015.

<sup>267</sup> Charmaz, *Constructing Grounded Theory*, 99.

<sup>268</sup> H. Hand, “The Mentor’s Tale: A Reflexive Account of Semi-Structured Interviews,” *Nurse Researcher* 10, no. 3 (2003): 15–27; Birks and Mills, *Grounded Theory: A Practical Guide*, 2011, as cited in Birks and Mills, *Grounded Theory: A Practical Guide*, 2015, 56.

<sup>269</sup> Y. S. Lincoln and E. G. Guba, *The Constructivist Credo* (Walnut Creek, CA: Left Coast Press, 2013), 70.

<sup>270</sup> J. Mills, A. Bonner, and K. Francis, “Adopting a Constructivist Approach to Grounded Theory: Implications for Research Design,” *International Journal of Nursing Practice* 12, no. 1 (February 1, 2006): 8, doi:10.1111/j.1440-172X.2006.00543.x.

Social constructionism is a term better known for its use in sociology. Only since the early 20<sup>th</sup> century, have psychologists adopted the term constructivism to describe related theoretical characteristics, within their own discipline. A key characteristic which has distinguished social constructionism from constructivism has been a debate about how theorists understand the extent of individual agency in the construction of meaning.<sup>271</sup> Constructionism proposes that meaning is socially constructed while constructivists confer meaning as cognitive and individual.<sup>272</sup> Social constructionists believe that, even though a group of individuals may all see or be witnesses to the same thing, the meaning each person ascribes to what is being observed is unique.

The disciplinary communities and theories, through which social constructionism and constructivism originated, have evolved in their understanding and use the concepts to the point where the terms are often used interchangeably or both subsumed under constructivism.<sup>273</sup> Within this thesis I will refer to social constructionism and constructivism specifically as they are cited in the literature. For the purposes of this research I will draw on social constructionism and constructivism as closely related bodies of knowledge which both contribute to theorising and positioning in this research.

Theorists in social constructionism and constructivism exhibit what Burr describes as having

a kind of 'family resemblance'. Members of the same family differ in the family characteristics that they share. There is no one characteristic borne by all members of a family, but there are enough recurrent features shared amongst different family members to identify the people as basically belonging to the same family group... There is no one feature, which could be said to identify a social constructionist position. Instead, we might loosely think of as social constructionist any approach which has at its foundation... key assumptions (from Gergen, 1985). You might think of these as something like 'things you would absolutely have to believe in order to be a social constructionist'.<sup>274</sup>

My journey into constructionist theory began with reading Kathy Charmaz's work in which she highlights the relationship between grounded theory as a methodology and "theorising as social actions". Charmaz begins to untangle constructivist notions within grounded theory research to expose its complexity particularly in studying how and why meaning is constructed. Constructivism and social constructionism are postmodern paradigms which acknowledge the experiences and perspectives of both participants and researchers as interpretive. Importantly, in second generation grounded theory, as "the resulting theory depends on the researcher's view", the interpretation is constructionist.<sup>275</sup> Theory is not

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<sup>271</sup> Burr, *Social Constructionism*, Kindle Location 436.

<sup>272</sup> R. A. Young and A. Collin, "Introduction: Constructivism and Social Constructionism in the Career Field," *Journal of Vocational Behavior: Special Issue on Constructivism, Social Constructionism and Career* 64, no. 3 (June 2004): 373–88, doi:10.1016/j.jvb.2003.12.005.

<sup>273</sup> Burr, *Social Constructionism*; Young and Collin, "Introduction: Constructivism and Social Constructionism in the Career Field."

<sup>274</sup> Burr, *Social Constructionism*, 2.

<sup>275</sup> Charmaz, *Constructing Grounded Theory*, 129–130.

neutral but rather an acknowledgement of the parts people and situated contexts play in the creation of knowledge.<sup>276</sup>

Researchers construct in concern with others in particular places and times. In addition to our research participants, colleagues, teachers, students, institutional committees and untold others may live in our minds and influence how we conduct our studies long after our immediate contact with them. We interact with data and create theories about it. But we do not exist in a social vacuum.<sup>277</sup>

Social constructionist perceptions of the world reflect complex social contexts and influences. “The ways in which we understand the world, the categories and concepts we use, are historically and culturally specific.”<sup>278</sup> Knowledge is contextual and socially constructed. Realities and truths are not simply “independent facts” but co-constructed in relationships with others.<sup>279</sup> Perspectives become multiple and acquired through social convention. This does not mean that we cannot come to shared understandings of knowledge as *truth*; rather knowledge is established in the context of its use. “Our constructions of the world are therefore bound up with power relations because they have implications for what it is permissible for different people to do, and for how they may treat others.”<sup>280</sup> There are fundamental assumptions which underpin the way social constructionists understand the world and our place in it. These concerns, listed below, are congruent with the intent of this thesis:

- “A critical stance toward taken-for-granted knowledge...
- Historical and cultural specificity...
- Knowledge is sustained by social processes...
- Knowledge and social action go together.”<sup>281</sup>

Social constructionism is multidisciplinary in nature and encompasses theorists who espouse the nature of reality and experience as socially constructed and multidimensional.<sup>282</sup> Reality is, for the social constructionist, constructed through all forms of cultural life such as: language, knowledge and symbols. As Gergen and Gergen explain the way in which we define or identify reality is by the same token constructed. Language and symbols are specific to cultures or traditions. Within another cultural context the same language or symbols may be imbued with very different meaning.<sup>283</sup> This differential in meaning challenges the assumptions we might make regarding even the most considered definitions.

There are many names for this revolution in thought and practice. Terms such as post-foundationalism, post-empiricism, post enlightenment and postmodernism are often among

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<sup>276</sup> A. Bryant, “Grounding Systems Research: Re-Establishing Grounded Theory,” in *Proceedings of the 35th Annual Hawaii International Conference on System Sciences, 2002. HICSS, 2002*, 3446–55, doi:10.1109/HICSS.2002.994383.

<sup>277</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 129.

<sup>278</sup> Burr, *Social Constructionism*, Kindle Location 120.

<sup>279</sup> K. J. Gergen, *An Invitation to Social Construction*, 2nd ed. (London: SAGE Publications, 2009), 4.

<sup>280</sup> Burr, *Social Constructionism*, 5.

<sup>281</sup> *Ibid.*, 2–4.

<sup>282</sup> *Ibid.*, 5.

<sup>283</sup> Gergen and Gergen, *Social Construction: Entering the Dialogue*, Kindle Location 122.

them. However, woven through all these discussions is the notion of social construction—that is, the creation of meaning through our collaborative activities. While social construction is neither authored by any single individual or group, nor singular and unified, there is substantial sharing across communities. Tensions and insecurities are not feared because to establish a final truth, a foundational logic, a code of values or one slate of practices would be contrary to the very unfolding of ideas championed by social constructionists.<sup>284</sup>

Fundamentally, it is social relationships and cultural traditions which underpin how individual perspectives and meaning are constructed.<sup>285</sup> The nature of the relationship between the human mind and body is one of sometimes more or less subtle contention. It is the topic of philosophical debate when considering what it means to be a whole person. Burkitt describes himself as a social constructionist with a particular interest in discourses regarding the construction of self and body. Burkitt believes that we experience reality as multi-dimensional. Reality is constructed through social worlds, and an embodied human experience. Social construction and materiality are not opposed to each other. Rather the creation of artefacts is part of having agency and being productive. The processes of social engagement and construction are evolutionary and reciprocal in terms of effect.<sup>286</sup>

### **3.3.4 The fit of second generation grounded theory with the principles of the records continuum as a framework**

It is my view that there is an excellent philosophical and procedural fit between the principles of second generation grounded theory (as a research process), the social constructionist lens and records continuum theory. The principles upon which Australian records continuum theory has been developed provide the theoretical framework for the choice of second generation grounded theory in this research project. Postmodern philosophical and sociological discourses have been pivotal forces in shifting how researchers in archival science “contemplate the societal implications and effects of archives and recordkeeping”.<sup>287</sup> These principles reflect how the evolving worldview of archival researchers embodies emergent continuum thinking which heightens awareness of complexity and mutability. Most importantly, records and archives are recognised as being sensitive to contexts and relationships; structural and human.

I have situated this study in a very specific human context, of the person with early stage dementia. This research seeks to understand the phenomena of individual remembering through the creation of personal records from the perspective of the people engaged in the activity and process. Fundamental to Australian records continuum theory is the concept of situated analysis which recognises that there are infinite dimensions to records in the lives of people and structures. Upward explains that, when describing continuum ‘mechanics’, topological thinking deals with modelling and the “logic of place”. Modelling here is a

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<sup>284</sup> Ibid., Kindle Location 72.

<sup>285</sup> Burr, *Social Constructionism*, Kindle Location 436.

<sup>286</sup> I. Burkitt, *Bodies of Thought: Embodiment, Identity and Modernity* (London: SAGE Publications, 1999).

<sup>287</sup> S. McKemmish and A. Gilliland, “Archival and Recordkeeping Research: Past, Present and Future,” in *Research Methods: Information, Systems and Contexts*, ed. K. Williamson and G. Johanson (Prahan, VIC: Tilde Press, 2013), 86.

technique for interpreting specific concepts and their relationships to each other in a framework for what Upward calls “any era – any place”.<sup>288</sup> Though words and concepts are the markers within this type of modelling they are less about defining their meaning and more about interpreting their meaning within time or place – as variants of contexts.

In this way, Upward’s situational analysis is an activity, a practice, and a process which is not fixed. Instead it opens up interpretations of the relationships between multiplicities and partialities to reflect subjectivities. It can serve to sharpen perspectives yet also help realise that ‘boundaries’ are defined only from the perspectives from which they are conceived. In this sense the perceiver is as much a part of the context and the construction of perception. This worldview of records continuum theorists is empathetic to the constructivist underpinnings of second generation grounded theory.

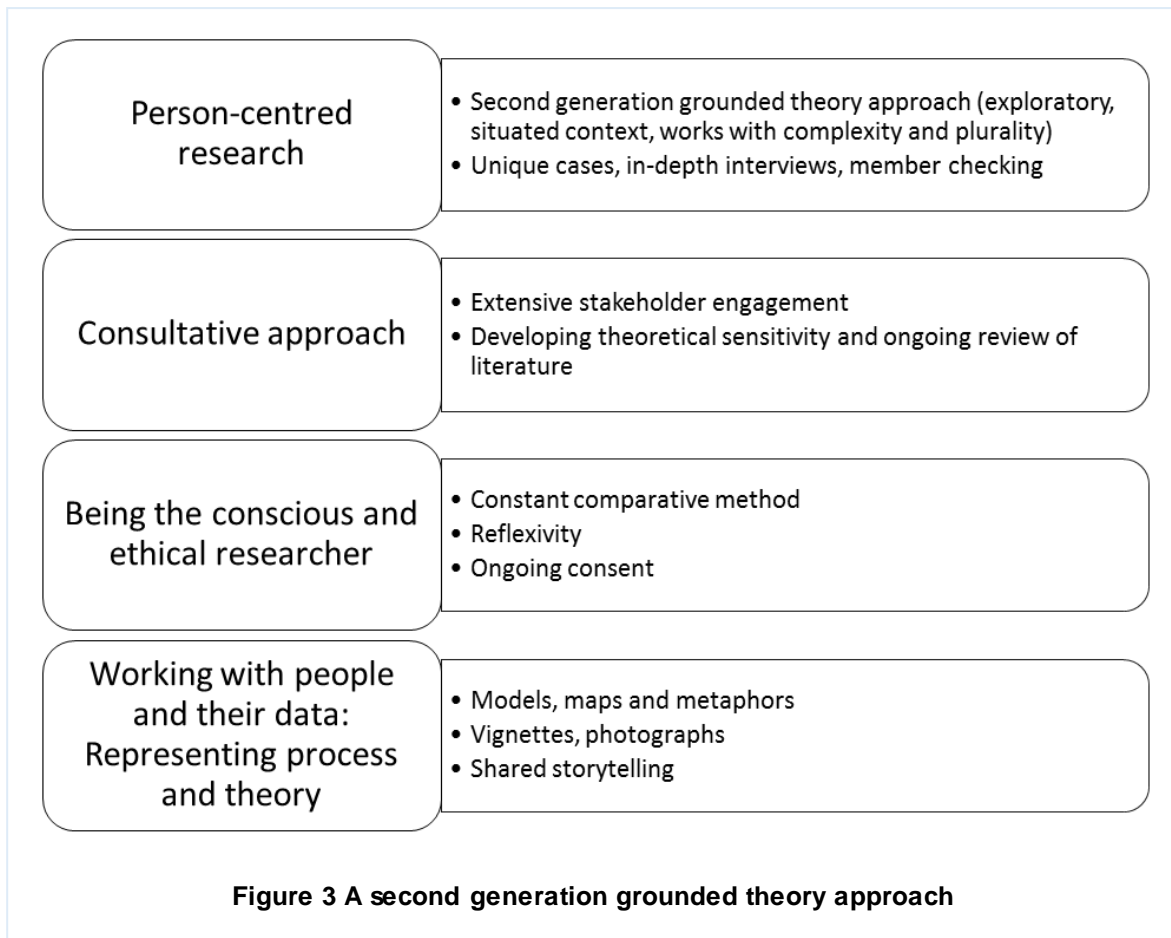
In conclusion, methodological wayfinding was a practical means for establishing the inductive and constructivist processes of grounded theory. Further, the tenets of social constructionism and constructivism also provided a framework for the philosophical underpinnings of the methodology. These arguably fit with the principles of records continuum thinking. Together these philosophic underpinnings and disciplinary assumptions about records created the framework for the conduct of this research.

### **3.4 *In Practice: Methodology, Methods and Techniques for Working with Complexity and Perspectives***

In this section I present the design and components of this second generation grounded theory; how they were implemented in practice within this applied archival research. In designing this study my intention was to create a holistic and sensitive approach to working with people and their data, which reflected the postmodern and social constructionist underpinnings of this research. Figure 3 provides a map of the overarching principles described in Section 3.2 in relation to the methods and techniques implemented in developing person-centred design, for the person with early stage dementia. The process of interviewing participants for the collection and analysis of data required complementary methods and techniques that respected their individual contexts and the phenomena of co-creating records.

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<sup>288</sup> F. Upward, “Continuum Mechanics and Memory Banks,” *Archives and Manuscripts* 33, no. 1 (2005): 85.  
3-71



These methods and techniques did not, each on their own, address a singular research aim or question. Denzin and Lincoln reinforce that there are many ways of doing the same thing. How things are done depends on politics and methodology.<sup>289</sup> “Each practice makes the world visible in a different way. Hence, there is frequently a commitment to using more than one interpretive practice in any study.”<sup>290</sup>

The methods and techniques reflected many ways of knowing and developing new knowledge. As such, in this section the methods and techniques are presented in relation to the researcher intent and principles, rather than a narrative sequence:

- Section 3.4.1: A second generation grounded theory approach which created a framework for exploratory research situated in unique personal contexts and able to work with complexity and plurality.
- Section 3.4.2: Recruitment and ethics.
- Section 3.4.3: Extensive stakeholder engagement helped me to understand broader contexts and then position myself and this research.
- Section 3.4.4: Ongoing review of the literature served to develop theoretical sensitivity, learn about the theory as well as practice; searching existing knowledge to understand what I observed in the research context.

<sup>289</sup> Denzin and Lincoln, *The Handbook of Qualitative Research*, 8.

<sup>290</sup> *Ibid.*, 4.



- Section 3.4.5: The constant comparative method provided a responsive approach to considering and integrating the components of the archival research process in working with participants, data, the archival product and theory building.
- Section 3.4.6: Reflexivity was expressed as conscious approach to working with people, the record and their interrelationships.
- Section 3.4.7: In-depth interviews which extended over months provided the time to ‘get-to-know’ the participant and explore the ‘art’ of crafting a record which supports memory and identity.
- Section 3.4.8: Ongoing consent meant that decision-making was a consultative process, for working with participants, serving to address individual needs as well as that of the research.
- Section 3.4.9: Shared storytelling, vignettes and photography were an important means of representing and reviewing the records with participants as they were created using form, text and images.
- Section 3.4.10: Models, maps and metaphors were my toolkit for analysing and communicating the various aspects of the research.

### **3.4.1 A rationale and design for second generation grounded theory in this research**

In considering the methodological approach to this research I was looking for a methodology which, as reflected by methodological wayfinding described in Section 3.3.1, would allow me to ‘feel my way’ through the research in order to ‘find’ a process that worked to answer the aims of this research questions and sensitively fit the person-centred context of the person with dementia. I needed a methodology which provided a strategy and guidelines but was not prescriptive. It would need to be able to adapt to what I would find throughout the course of the research rather than prescribe the framework into which it would need to fit.

Gilliland and McKemmish described the generation of grounded theory as useful, in archival literature, for “exploratory research where little is known about a particular situation or phenomenon”. Examples of research given in relation to this description reflect a non-specific approach to working with data rather than grounded theory as the methodology.<sup>291</sup> The implementation of traditional grounded theory or second generation grounded theory is still very rare in archival science.<sup>292</sup>

Second generation grounded theory is particularly appropriate to this research as it provides “processes and a path” to study the situated context which are very adaptable to diverse studies. Second generation grounded theory has traits which allowed me to ensure that the data collected and the products of the research would represent process, perspectives and meaning with a certain acuity. The traits of this second generation grounded theory included:

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<sup>291</sup> A. Gilliland and S. McKemmish, “Building an Infrastructure for Archival Research,” *Archival Science* 4, no. 3–4 (February 2006): 178, doi:10.1007/s10502-006-6742-6.

<sup>292</sup> J. Bunn, “Grounded Theory: A Straightforward and Complicated Exposition,” in *Research in the Archival Multiverse*, ed. A. J. Gilliland, S. McKemmish, and A. J. Lau (Clayton, VIC: Monash University Publishing, 2016).

- Sensibility to the research context as a reflexive process
- Being sensitive to the role of the researcher and the relationship with participants
- Respecting the integrity of the participant and their data
- Dealing with complexities and multiple perspectives in a postmodern world
- Exploring situated contexts and situated knowledge.

#### **3.4.1.1 Sensibility to the research context as a reflexive process**

I wanted to explore the creation of the personal records and the personal archive in a context in which there was both an immediate purpose and some urgency for their use. Situating the research in the context of the person with dementia allowed me to hone in on how sensitive we as human beings are to our memories and how they are represented and used. It is a sensitive context requiring research methods that do not impose on the participants but rather frees them to determine what is important and why.

A second generation grounded theory approach enabled me to “feel my way” through the whole research process so that I could work out what was the most appropriate approach to all its various components: human, theoretical and processual. In particular it allowed me to construct a modified grounded theory approach ‘fit’ specifically for the purposes of this research which would also tolerate being adapted when required.

In constructing a grounded theory approach which is empathetic to the perspective of the person with dementia it was essential to take a ‘bottom-up’ approach to collecting and analysing data to develop processes and theory. It allowed me to try methods and techniques for data collection, evaluate their effectiveness and change the approach if necessary. It was important to analyse as well as define the different phases of research processes to progressively learn from what I had done.

It was a reflexive approach to research design which coerced me to confront at each step who I am, what I believe or think I know and the impact of my entering the lives of people in the name of ‘research’. The methods and techniques in this second generation grounded theory research allowed the participants and I to co-create records and explore their unique meanings.

#### **3.4.1.2 Being sensitive to the role of the researcher and the relationship with participants**

I needed to acknowledge that the way I ‘played’ out my role as the researcher was an influencing factor not only for the outcomes of the research but also for the participants’ experience of the research activities. We are involved in the co-construction of reality and I was conscious that ethical behaviour is an integrated process in which all my decisions and knowledge are interrogated.

Gubrium and Holstein describe the postmodern qualitative researcher as being increasingly self-conscious regarding how methodology reflects on the construct and representation of social reality. So much so, that “research procedure constructs reality as much as it produces

descriptions of it.” Understanding that the social world is constructed sensitises the researcher to how much a part they play in its actual construction when there is “multiplicity of experiential realities that might be created, including the reality of method as a way of knowing”. As this realisation blurs the relationship between the researcher and participant it raises questions regarding how a researcher becomes “up close and on the scene”.<sup>293</sup>

#### **3.4.1.3 Respecting the integrity of the participant and their data**

The integrity of this research relied on hearing and respecting the voice of the participant from their perspective and in their context. I wanted to interview the participants in their own homes to ensure they felt safe and comfortable. The constant comparative method (explained in detail in Section 3.4.5) for data collection and analysis promoted ongoing and iterative conversations with participants to hear their ‘perspectives’ and identify concepts over a period of time. This method takes the pressure off both the researcher and participants to deliver ‘answers’. Instead there is time to explore together memories, recordkeeping concepts and meaning and the uniqueness of each participant.

The theoretical assumptions in second generation grounded theory uphold the integrity of the research questions by nurturing a person/participant-centred approach to the phenomena being studied. Each person’s perspective including that of the researcher is subjective and subject to interrelated contexts in their construction and co-construction. These dimensions of reality are encouraged and not judged. The data collected were submitted for scrutiny through review with participants; to evaluate how they ‘fit and work’. The methods must fit the purpose so that the integrity of the participant and their data are respected throughout the research process. Getting as close as possible to the participant served the purpose of listening and reflecting ‘multiple realities’ in the representation of data.

#### **3.4.1.4 Exploring situated contexts and situated knowledge**

In creating personal records I needed to understand and develop knowledge as something which is situated and constructed through experience and reflexive relationships with people, language, culture and traditions. This is important from a theoretical perspective. It is also significant when exploring and representing situated knowledge of ‘self’ which is also constructed.

The grounds for new methodologies are warranted when those existing methodologies, defined by a strategy, do not adequately support exploring certain situated knowledges.<sup>294</sup> Grounded theorists such as Clarke and Charmaz have *evolved* the methodology with new approaches that reflect their own experiences as well as changing philosophical and theoretical influences.

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<sup>293</sup> Gubrium and Holstein, *The New Language of Qualitative Method*, 10–11.

<sup>294</sup> Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*, xxv.

### 3.4.1.5 Dealing with complexities and multiple perspectives in a postmodern world

The research needed to be able to work within the ambiguity that exists in the contexts of the experience of the person with dementia and the notion of personal records. It had to encompass multiple perspectives and deal with the inherent complexities of creating personal records through representation of content in a medium and with meaning. Here responsibility rests upon me as the researcher to address societal challenges founded on ethical and reflexive practice, which acknowledge the complexities and multiple perspectives of society.

Second generation grounded theory allowed me as a researcher to open up new methods to empirical understandings grounded in a postmodern world.<sup>295</sup> Here responsibility rests upon the researchers to address societal challenges founded on ethical and reflexive practice which acknowledges the complexities and multiple perspectives of society.

The design of this study was informed by Charmaz's view that grounded theory research emerges through the researcher's situated interactions. The design for this study has considered situated contexts as a defining factor in relation to theory, process and the evolving products of the research. It is flexible in that the practices were developed in response to interactions with the subject and the contexts being studied. Grounded theory as a methodology acknowledges that sensitising concepts and theoretical frameworks already inform our worldviews. Rather than being used for deductive logic these theoretical frameworks are, as Charmaz says, essential in positioning the research in "relevant disciplines and discourses".<sup>296</sup>

Addressing the research aims and questions demanded an integrated approach in response to the type of information or data being collected and the theory being developed. The chosen methods provided a process for not only collecting data but analysing and representing that data in a meaningful way for both the participant and the researcher. As a second generation grounded theory, one of the aims was to explore the record not as a predefined concept but as the essence of what is represented and how. Co-creating records in this case served as a physical and tangible model for exploring the personal record – explicit and tacit – as well as creating a meaningful representation.

To hear the person's voice required listening to what they thought, said and did. I needed to find methods which would encourage an approach that was inclusive and collaborative. Second generation grounded theory supported the decisions to use a toolkit of methods to explore creating a records grounded in the personal experience. It provided a framework and the systematic thinking through the constant comparative method for collection and analysis of data which encourages the researcher to look for 'enlightenment' in each 'moment' of the activity, process and data. It is a reflexive approach to practice. As the researcher, I learned from the participants in the research and brought what I learned back into the research process. Through the construction of personal records, knowledge is also constructed.

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<sup>295</sup> Ibid., xxvi.

<sup>296</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 169.

The research design brought together a range of methods within the framework of second generation grounded theory and the records continuum. How could I study the phenomena of co-creating records that reflect memory and identity in a way that respects the activity of remembering and the representation of those memories? Studying the phenomena of remembering through creating personal records in postmodern and constructivist paradigms makes it necessary to understand the impact of the paradigm on how we understand remembering. Bruner describes the self as not being only remembered but rather a cognitive activity in which self-narratives through self-construction reveal multiplicity of selves which vary according to context.<sup>297</sup>

In order to explore this multiplicity of self and its effect on the record creation activity, engaging with participants would have to occur on a series of occasions to observe the patterns and differences. The methods and techniques used to create personal records would need to be able to reflect perceptions, representations and meaning in a way that would be tangible and would make sense to the participant as well as the researcher. The methods and processes would need to be developed in context to ‘see’ what would work and what would not for each individual participant. It might sometimes be a case of trial and error – but not at the expense of the participant. An ethical approach to the research would need to be built on respect for the participant, their home, family and data. Trust and openness could not be assumed but embedded in a responsive and caring relationship with all parties.

The purpose of this second generation grounded theory study and empirical research was to understand concepts as they were being shaped and experienced within the context of their use. We had created records of personal meaning. I wanted to understand how these records were representative of personhood and the affordances of this record creation process which made them person-centred.

Discourses regarding the quality of social research continue to raise questions regarding how qualitative research is both undertaken and judged. This is particularly important as “Any theoretical rendering offers and interpretive portrayal of the studied world, not an exact picture of it. Research participant’s implicit meanings, experiential views – and researchers’ finished grounded theories – are constructions of reality.”<sup>298</sup>

Seale argues that the nature of quality is in itself elusive in that “we somehow recognize it when we see it, but we cannot specify it with methodological rules”.<sup>299</sup> Others have, in emphasising the postmodern turn, tussled with the terminology and concepts referenced in judging qualitative research. In reporting the findings of grounded theory research, the focus lies in elaborating the processes undertaken in order to collect, analyse and build theory with the data. The context of this research adds the need to make explicit the processes for

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<sup>297</sup> J. Bruner, “The ‘Remembered’ Self,” in *The Remembering Self: Construction and Accuracy in the Self-Narrative*, ed. U. Neisser and R. Fivush (Cambridge: Cambridge University Press, 1994), 41–54.

<sup>298</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 10.

<sup>299</sup> C. Seale, “Quality in Qualitative Research,” in *Turning Points in Qualitative Research: Tying Knots in a Handkerchief*, ed. Y. S. Lincoln and N. K. Denzin (Lanham, MD: AltaMira Press, 2003), 170.

working with people as well as their data. A toolkit of methods and techniques was implemented to explore and make transparent the perspectives of the individual participants and how these impacted on decisions of both participants and researcher.

In this section I presented the philosophic principles that were implemented in this second generation grounded theory research. Five traits of the grounded theory researcher were identified and described. These were: using sensibility in the research context as a reflexive process; being sensitive to the role of the researcher in relationship with the participants; respecting the integrity of the participants and their data; dealing with complexities and multiple perspectives in a postmodern world; and exploring participants' situated contexts and situated knowledge. Together these five traits created a holistic approach for working with people in sensitive ways.

### 3.4.2 Recruitment and ethical approval

Having reported on the philosophic principles that were actualised in this research it is now important to address some steps, stages and processes that occurred in practical undertaking of this project. Recruitment and ethical approval is a key step (see Appendices 1, 2, 3 and 4)

In this section I report on the recruitment of the participants in this research project and on the achievement of ethical approval. As an interpretive bricoleur (described in Section 3.3.1), I was consciously selecting methods and techniques which would allow me to focus on the individual perspectives of the people with early stage dementia as participants in this research. Co-creating person-centred records was explored in relation to the unique experiences of three people with dementia. There was "a focus on concrete cases in particular contexts" in order to better understand the research in practice.<sup>300</sup> Dementia and its effect on a person's memory and identity was a motivating factor for focusing on the individual and their perceptions in this research context. One of the participants had early onset as well as early stage dementia (diagnosed prior to 65 years of age). I spent three months, working with each of the participants, exploring their memories, stories and what gave meaning for them.

Using second generation grounded theory and the constant comparative method (described in Section 3.4.5) for the collection and analysis of data enhanced the exploration of in-depth and rich case data. Siggelkow highlights that "a single case can be a very powerful example" when he engages in a discourse on the effectiveness of the single case to persuade. As he explains it is not the size of the sample which matters but rather the insights that the case is able to provide. There are at least "three important uses for case research: motivation, inspiration, and illustration." A case can motivate a research question: it can provide conceptual insight and demonstrate why a phenomena is important, either theoretically or as a real-life example. It is the "rich case data" collected which inspires theory to emerge where theory is limited or needs to be developed. The same case which inspires the research problem has the potential to illustrate through a contribution to the concepts as well as the theory.<sup>301</sup>

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<sup>300</sup> Pascale, *Cartographies of Knowledge: Exploring Qualitative Epistemologies*, 143.

<sup>301</sup> N. Siggelkow, "Persuasion with Case Studies," *The Academy of Management Journal* 50, no. 1 (February 1, 2007): 20, doi:10.2307/20159838.

This research was not designed as a clinical study. The sampling strategies were informed by the purpose of the study and the available resources.<sup>302</sup> The situated context of prospective participants was that of being ‘diagnosed’ with dementia but the dementia was not the topic of the research. This research was person focused. I was seeking participants still living independently or with some support in the community.

Participants in this study were aged 62 years and over. Each participant had a diagnosis of early stage dementia and was still living in their own homes in the community. While this is a small number of participants, the data collection process with each participant extended over several weeks and in-depth interviews. It was not the purpose of the research to focus on generalising the findings. Instead the intent was to examine the characteristics which were unique or common to the people who participated in the research and their records.

The call for participants commenced in August 2011 via the Alzheimer’s Australia website and newsletter, although in the end participants were recruited via synergistic channels.<sup>303</sup> In searching other avenues to promote the call for participants I distributed the information sheet to interested attendees at the National Dementia Research Forum later in 2011. This resulted in two participants expressing interest via the Commonwealth Respite and Carelink. The third participant heard about the project via a *Monash University News* article.

It was important to consider the impact on participants and researchers in undertaking sensitive research, which has been described extensively in literature. As Liamputtong explains, making contact with people who are vulnerable or who might be sensitive about their experiences can be a challenge.<sup>304</sup> Depending on the progression of dementia, a person’s daily activities may be supported or facilitated by a carer. It can be quite difficult to recruit participants for a research project. This has much to do with the way individuals and families cope within the framework of their personal resources and changes associated with dementia. Participating in a research project is not necessarily on the list of priorities when there are so many other factors to contend with. Sometimes even making that initial phone call can be difficult.

A pre-requisite for conducting research with human participants, particularly in what might be considered a sensitive context, was the completion of Monash University’s human ethics approval process. After the research was designed, the ethical approval was sought and granted by Monash University Human Ethics Committee (CF10/3507 – 20110001867) on 8 April 2011 (Appendix 1). No amendments were made throughout the course of the research.

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<sup>302</sup> Patton, *Qualitative Research and Evaluation Methods*, 243.

<sup>303</sup> In the first year of my PhD I developed a relationship with Alzheimer’s Australia which is the peak body in Victoria “dedicated to supporting people with dementia, their families and carers.” Their services also include advocacy and research, and they are vitally concerned with the safety and wellbeing of people with dementia. Advocacy groups such as Alzheimer’s Australia also recognise the need to hear more of the voice of the person with dementia in the realm of research. Upon seeking advice from Alzheimer’s Australia on recruiting participants for the project, they posted the call for participants in their newsletter and on the association’s website.

<sup>304</sup> Liamputtong, *Researching the Vulnerable: A Guide to Sensitive Research Methods*, 58.

Formal ethics approval was granted prior to commencing recruitment and interviewing participants, yet, ethical practicing was an ongoing consideration and influencing factor throughout the study. Section 3.4.8 discusses the concept of ongoing consent as practiced within this research.

### 3.4.3 Extensive stakeholder engagement

While recruiting and interviewing participants was important, so too was talking with other people who have extensive expertise. In this section I report on the steps and processes I used to engage relevant stakeholders in conversations about this project.

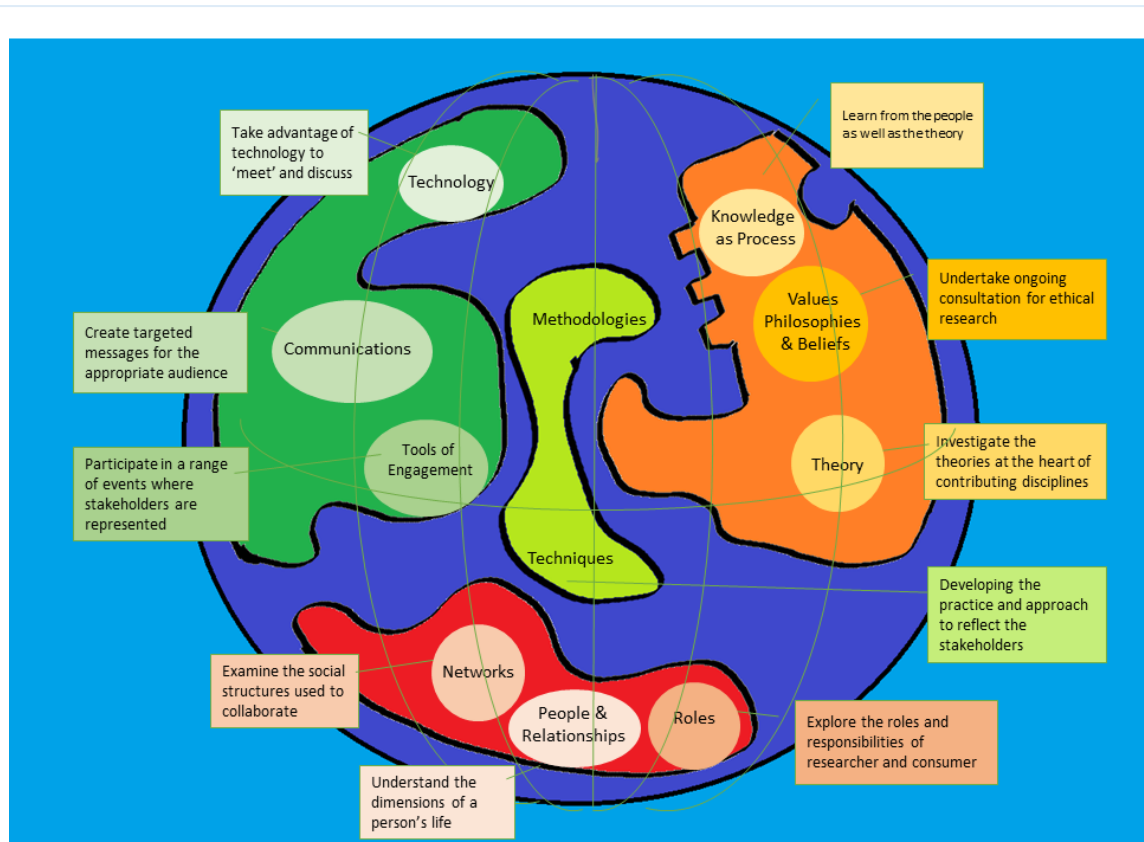
Extensive stakeholder engagement was an important activity for understanding the broader contexts, academic and practitioner, influencing the participants in this study. It was extensive stakeholder engagement which helped me to define the currency and relevance of the knowledge I was exploring in this research. Key stakeholders and target audience included: institutions, funding bodies, academics, advocacy and professional associations, the media and the general public. It became evident even in the early stages of scoping this research that I could learn much from the specialist disciplines which were interested in this problem area of supporting memory and identity for people with dementia and particularly the use of personal records. Even though I had worked as a nurse many years ago, I felt out of touch in terms of how to gauge what was the most up-to-date research and practice in the area of dementia and aged care particularly across disciplines. In my more current work as a knowledge manager and business analyst I had engaged with stakeholders as an important but routine activity. In undertaking a research project, which would eventually be scrutinised and critiqued through the dissemination of reports, I considered it essential to consider who the potential audience and stakeholders might be.

Due to the experience of undertaking this research across disciplines, I adopted a very broad understanding of stakeholder engagement. Bammer describes stakeholders, particularly in the context of cross-disciplinary research, as those who have “a practical grasp of the problem. a) those affected by the problem, and b) those in a position to influence a problem.”<sup>305</sup> The implications of this definition mean that the broader effects of research from its inception through to eventual dissemination, may impact on the various stakeholders both directly and indirectly.

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<sup>305</sup> G. Bammer, *Disciplining Interdisciplinarity* (Canberra, ACT: ANU E Press, 2012), 16, [http://press.anu.edu.au/apps/bookworm/view/Disciplining+Interdisciplinarity/10241/commentaries.html#toc\\_marker-10](http://press.anu.edu.au/apps/bookworm/view/Disciplining+Interdisciplinarity/10241/commentaries.html#toc_marker-10).





**Figure 4 Reflecting on extensive stakeholder engagement**

The map in Figure 4 represents an analysis of the stakeholder engagement process I undertook in the course of the research. Reflecting on this range of activities highlighted not only how those activities had contributed to this research design but importantly the lessons I had learned in identifying and communicating with stakeholders. It reflects the spirit of methodological wayfinding to see a big picture view of a research project as well as the value of its parts. The stakeholder engagement was mapped to identify the discrete concepts, activities and their relation to the research. [The map and the lessons learned were the focus of a conference poster presentation. (See Appendix 5)]

Stakeholder engagement provided an iterative approach to concept building and research design in relation to real world theory and practice. These activities allowed me to:

- Define the research problems in relation to the relevant disciplines
- Challenge and refine the research problems, methodologies and protocols in a way that is value sensitive
- Validate these research concepts with experts so that the concepts make sense in the real world both theoretical and practical
- Scope the project into something that could be done within the framework of a PhD project and thesis, undertaken by a single person
- Design and build a project that meets a range of criteria and needs: methodological, philosophical and pragmatic when working with people with dementia.

Having experienced the outcomes from the extensive stakeholder engagement, I hold the view that these activities can be an important part of grounded theory research. Further, that the value may also lie in their expertise related to working with sensitive and vulnerable communities.

### 3.4.4 Developing theoretical sensitivity and the ongoing review of literature

In keeping with grounded theory processes, developing theoretical sensitivity and ongoing review of the literature was an important process in the research. It is important to recognise that ongoing review of the literature continues during the recruitment and interviewing of participants and while ongoing stakeholder consultation is progressed.

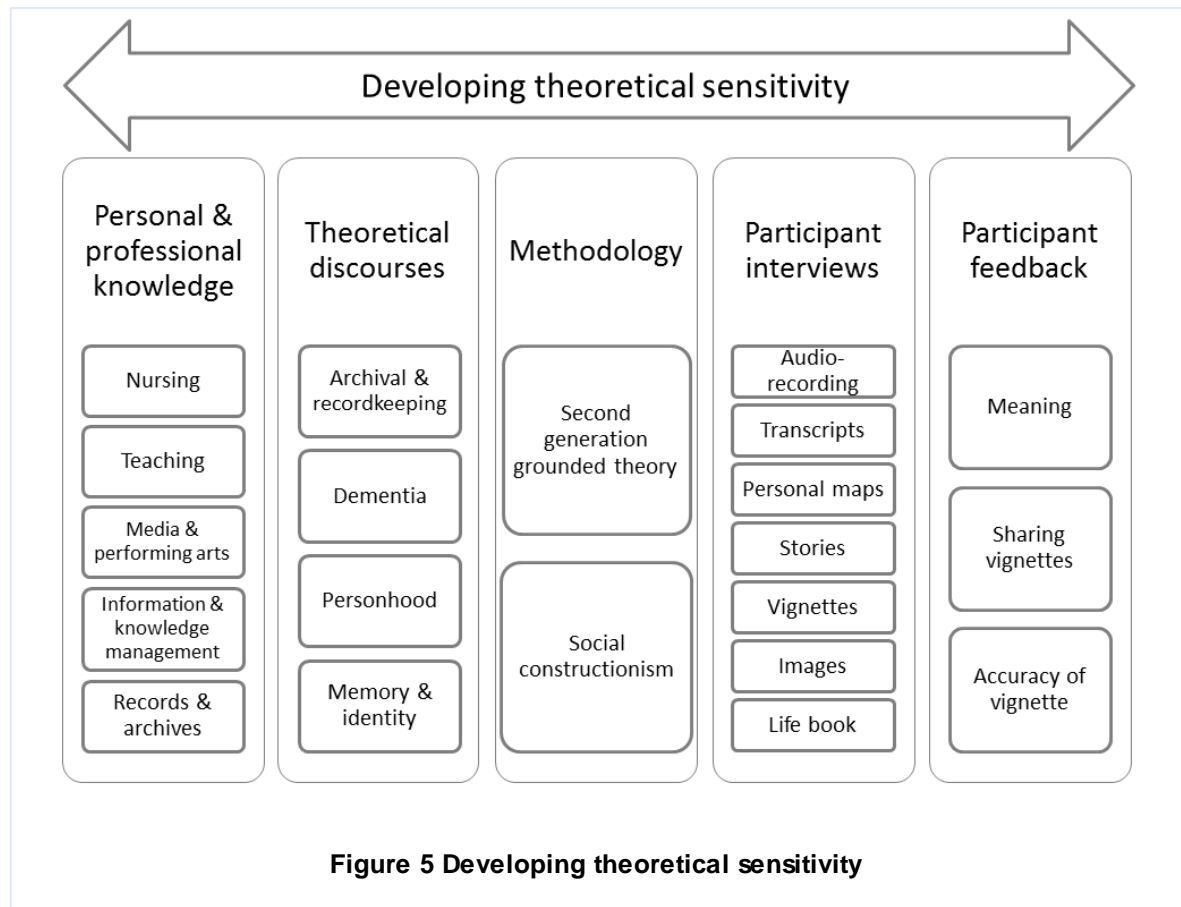
The extensive stakeholder engagement described in the Section 3.4.3 was part of a broader approach to developing theoretical sensitivity and new knowledge in this second generation grounded theory research.<sup>306</sup> In Chapter 2 I introduced the concept and activity of developing theoretical sensitivity, within which the ongoing review of literature is fundamental. As illustrated in Figure 5, developing theoretical sensitivity was guided by: my disciplinary expertise, theoretical discourses and methodology which informed this research context. “The literature provided material for enhancing my theoretical sensitivity, understanding the context of the study and explaining the subsequent theory, but it was the participants’ experience and my elicitation of it with them that formed the fodder for analysis.”<sup>307</sup> Emergent codes and concepts directed and helped refine the investigation to develop a grounded theory.<sup>308</sup>

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<sup>306</sup> Though the predominant source for peer-reviewed knowledge is academic literature, there was also much to be learned from engaging with the academics and practitioners who contributed to those bodies of knowledge. I participated with other academics and practitioners in knowledge sharing forums. According to McKemmish and Gilliland authoritative sources are not limited to codified expert knowledge but may also be found in oral and literary texts as well as domain experts. McKemmish and Gilliland, “Archival and Recordkeeping Research: Past, Present and Future,” 103.

<sup>307</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015, 172.

<sup>308</sup> The function, purpose and timing of the literature review in grounded theory research has been vigorously debated. It is generally agreed that the aim is to steer clear of the literature specific to the topic and read in broader terms. This is all part of the process of developing theoretical sensitivity. G. McGhee, G. R. Marland, and J. Atkinson, “Grounded Theory Research: Literature Reviewing and Reflexivity,” *Journal of Advanced Nursing* 60, no. 3 (November 1, 2007): 334, doi:10.1111/j.1365-2648.2007.04436.x.



The aim of second generation grounded theory is to develop theory about salient aspects of the research findings which are refined through theoretical sampling and analysis. The construction of codes, categories and theorising is built on a range of data collected and created through the process of developing theoretical sensitivity. There were times I understood in principle what I was seeing. There were other times I referred to literature to provide further insight so that I could put words to what I was observing. This is important because the observations were about social and relational processes between people which sit outside the theoretical frameworks of archival theory. The experience of developing theoretical sensitivity was extended and deepened through the research process. “As a grounded theorist becomes immersed in the data, their level of theoretical sensitivity to analytical possibilities will increase.”<sup>309</sup>

Reviewing literature served specific purposes which correlated with distinct research activities. The aim of reviewing literature across disciplines in this context is grounded in the need to be open to the emergent themes which are explored and identified throughout the course of the research. This cross-disciplinary review of literature contributed to a richer understanding of the research problem and its context. The activities and sources which supported developing theoretical sensitivity are listed in Table 3, relative to key research activities.

<sup>309</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015, 12.

**Table 3 Sources explored in developing theoretical sensitivity**

<b>The literature was located through:</b>	<ul style="list-style-type: none"> <li>• Key word searches of online academic databases for peer-reviewed literature across disciplines.</li> <li>• The use of online search engines.</li> <li>• Advice of my supervisors particularly in relation to the archival literature.</li> <li>• Monash Library and my own burgeoning library of books and resources.</li> <li>• Following up on speakers at conferences as well as other professional and academic forums.</li> </ul>
<b>Scoping the research &amp; developing the research proposal</b>	<ul style="list-style-type: none"> <li>• Explore the research problem as key concepts and associated disciplines: <ul style="list-style-type: none"> <li>• Map the research context holistically: as a landscape, environment, dementia, memory &amp; identity.</li> <li>• Determine the contributions of others through what had already been done on the topic.</li> </ul> </li> <li>• Define the research questions.</li> <li>• Define relevant leading stakeholders, disciplines, concepts and theories.</li> <li>• Identify the gaps in current research.</li> <li>• Determine the literary warrant.</li> </ul>
<b>Sensitising concepts</b>	<ul style="list-style-type: none"> <li>• Study the literature in relation to: <ul style="list-style-type: none"> <li>• Person diagnosed with dementia</li> <li>• Personhood</li> <li>• Research methodologies</li> <li>• Social constructionism</li> <li>• Postmodernism</li> <li>• A participatory epistemology</li> <li>• Personal records</li> <li>• Records continuum theory</li> </ul> </li> </ul>
<b>Stakeholder engagement</b>	<ul style="list-style-type: none"> <li>• Participate in discourses related to the research problem and research context.</li> <li>• “Learn from and assimilate what is already known and enter into the conversation from a critical and creative standpoint.”<sup>310</sup></li> <li>• Position the research in disciplinary contexts.</li> </ul>
<b>The research design</b>	<ul style="list-style-type: none"> <li>• Define the philosophical and theoretical underpinnings of the research.</li> <li>• Determine the most suitable research approach considering this situated context.</li> </ul>
<b>Theory building: analysing and interpreting findings</b>	<ul style="list-style-type: none"> <li>• Examine and interpret the findings in light of existing theory.</li> </ul>
<b>The reading and analysis of literature was supported by the use of technology</b>	<ul style="list-style-type: none"> <li>• NVivo for analysing and coding archival literature.</li> <li>• Mindjet MindManager mapping software for the analysing of themes, codes and concepts.</li> <li>• Zotero free online bibliographic data management tool for storage, analysis and management of references. <ul style="list-style-type: none"> <li>○ I stored entries in files according to relevant categories, topics and themes.</li> <li>○ Bibliographic data were tagged with key words and concepts as further defining metadata.</li> <li>○ Reflective notes and memos were added.</li> <li>○ Zotero was used for referencing and citation within Microsoft Word.</li> </ul> </li> </ul>

<sup>310</sup> L. D. Bloomberg and M. Volpe, *Completing Your Qualitative Dissertation: A Road Map From Beginning to End* (Thousand Oaks, CA: SAGE Publications, 2012), 74.

### 3.4.5 The constant comparative method for the collection and analysis of data

The ‘constant comparative method’ is an accepted model for progressive and iterative working during grounded theory studies. In this section I report in some depth on the processes that I used in practice as expression of the constant comparative method. These are: ‘coding in grounded theory’, ‘theoretical memo-writing’, and ‘practising the constant comparative method’.

The constant comparative method for the collection and analysis data was an integral part of an integrated approach to this second generation grounded theory research. The constant comparative method, as described in grounded theory research, stipulates the importance of systematic, cumulative and concurrent collection and analysis of data.<sup>311</sup> The analysis of new data as it was collected allowed me to see and learn from what emerged in time and in the particular context. This learning was then incorporated into the subsequent data collection.

The constant comparative method complemented the underpinning records continuum theory, postmodern perspective, social constructionism and participatory epistemology, in which the record, memory and identity were multifaceted and ever evolving. According to Rorty, knowledge can only be clarified through interaction and communication.<sup>312</sup> This is an important factor to consider when creating person-centred records within a postmodern theoretical paradigm which “rejects the idea that there is a single reality or truth; rather, there are many realities and many truths. People have different stories and different ways of saying and expressing their stories.”<sup>313</sup> “Social constructions and questionable discourses are increasingly seen to dominate knowledge; meanings become recognised as individual creations, which require interpretation and negotiation.”<sup>314</sup> Figure 6 provides an overview of the range of data collected, and the analysis techniques implemented in relation to participant interviews in this research.

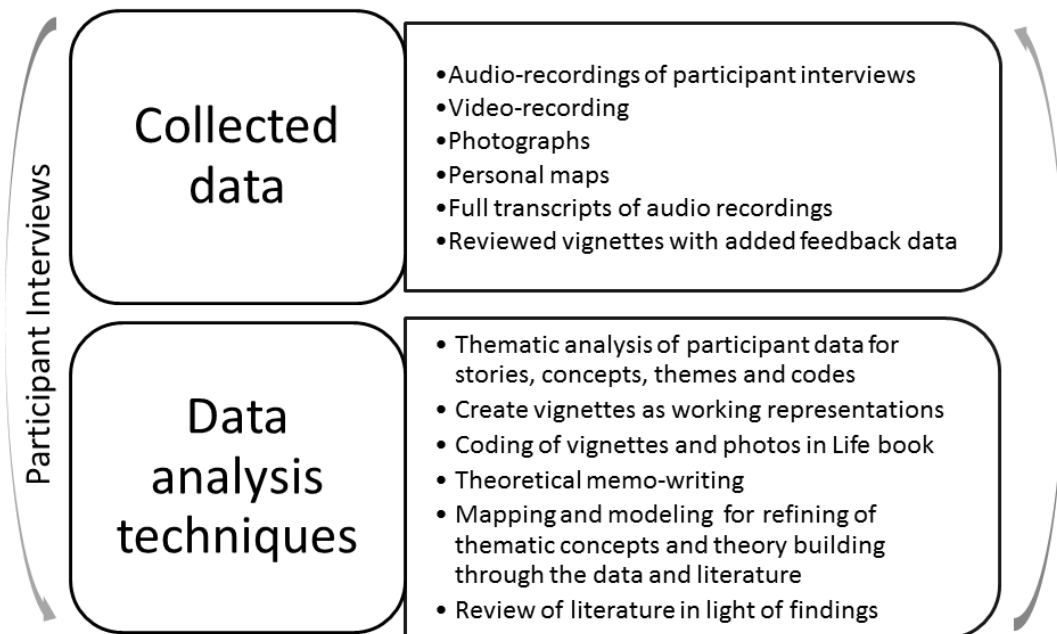
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<sup>311</sup> B. G. Glaser, “The Constant Comparative Method of Qualitative Analysis,” *Grounded Theory Review* 7, no. 3 (November 29, 2008), <http://groundedtheoryreview.com/2008/11/29/the-constant-comparative-method-of-qualitative-analysis-1/>.

<sup>312</sup> R. Rorty, *Philosophy and the Mirror of Nature* (Princeton, NJ: Princeton University Press, 1980).

<sup>313</sup> Liamputtong, *Researching the Vulnerable: A Guide to Sensitive Research Methods*, 15.

<sup>314</sup> C. Grbich, *New Approaches in Social Research* (London: SAGE Publications, 2004), 25.



**Figure 6 Overview of data collected and analysis techniques**

The process of the constant comparative analysis was guided, in particular, by second generation grounded theorists Charmaz, Urquhart and Clarke, all of whom emphasise that grounded theory techniques are developed from the data with distinct phases of coding and theory building.<sup>315</sup>

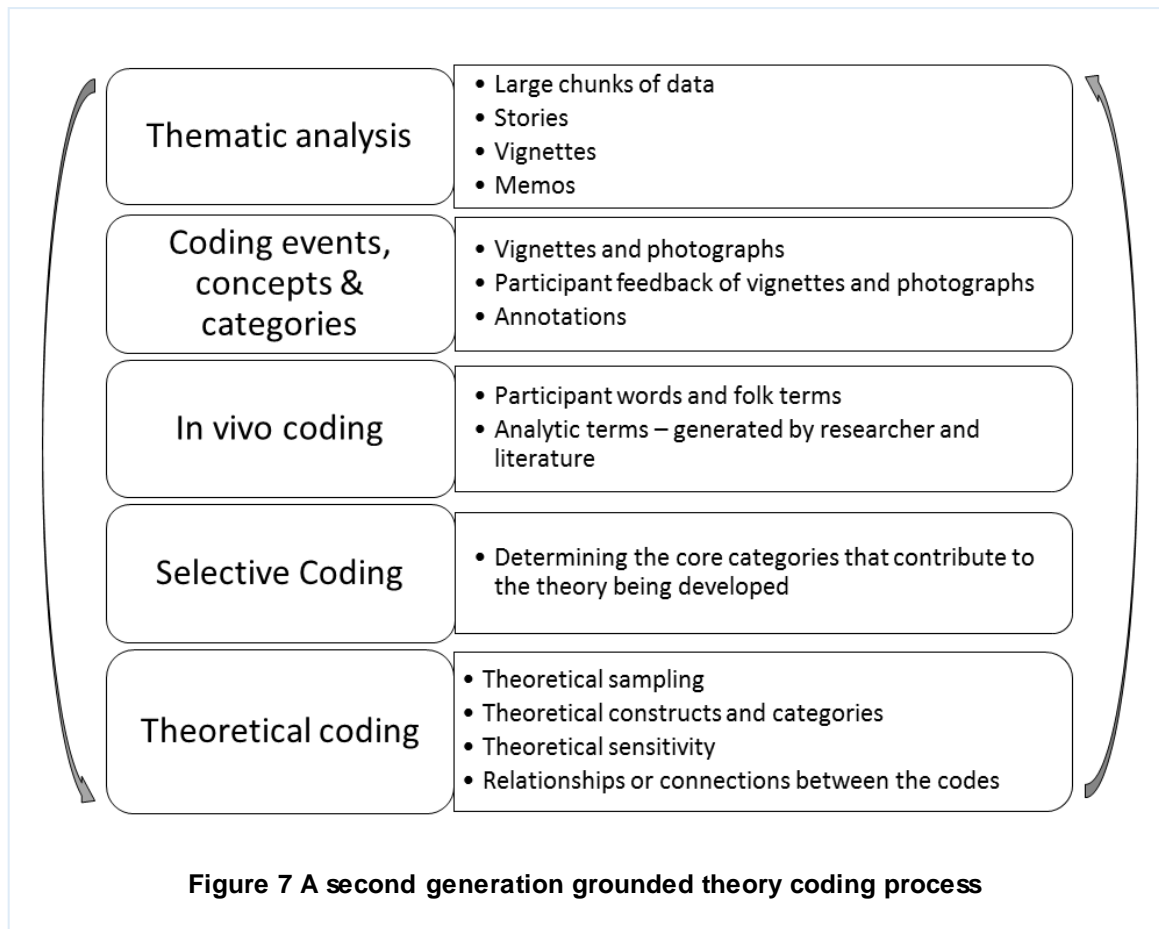
#### **3.4.5.1 Coding in grounded theory**

In grounded theory there is a range of specific techniques suited to developing levels of analysis and abstraction.<sup>316</sup> Charmaz explains that the type of coding used is dependent on the “the type of data...collected, their level of abstraction, the stage of the research process and your purpose for collecting these data”.<sup>317</sup> The levels of coding are listed Figure 7 in relation to the data being coded using that method.

<sup>315</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*; Urquhart, *Grounded Theory for Qualitative Research: A Practical Guide*; Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*.

<sup>316</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 42.

<sup>317</sup> Ibid., 53.



Though thematic analysis on its own is not typical in grounded theory, the inherent principles were used here to further support reflexive practice within the distinctive grounded theory coding techniques. Boyatzis describes thematic analysis as developing a sensibility whilst collecting and analysing data; there are three distinct phases of enquiry “Observation precedes understanding. Recognising an important moment (seeing) precedes encoding it (seeing it as something), which in turn precedes interpretation.”<sup>318</sup> This conscious process in the phases of thematic analysis provided essential insight for identifying the ‘codable’ moments as much as the codes.

- The **coding of events** was particularly suited to analysing for individual vignettes and associated photographs where it was important to maintain the integrity of the narrative for the creation of personal records.<sup>319</sup>
- **In vivo coding** was used to “preserve participants’ meanings of their views and actions in the coding itself”.<sup>320</sup>
- **Selective coding** was used in identifying those codes and categories which were clearly related to the research problem.

<sup>318</sup> R. E. Boyatzis, *Transforming Qualitative Information: Thematic Analysis and Code Development* (Thousand Oaks, CA: SAGE Publications, 1998), 1.

<sup>319</sup> Charmaz provides an in-depth discussion of coding events, which Charmaz describes as coding incident to incident, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 53.

<sup>320</sup> *Ibid.*, 55.

- **Theoretical coding** was used to conceptualise and construct the substantive codes in their relationships to each other and to theory.<sup>321</sup>
- **Selective coding** is also described as intermediate or focused coding.<sup>322</sup> This phase produces codes which “are more directed, selective and conceptual than word-by-word, line-by-line, and incident-by-incident coding”.<sup>323</sup> Selective coding is a process of “linking together or integration of concepts and categories. Concepts, categories and their sub-categories are compared with each other while the researcher”.<sup>324</sup>

Selective coding is a critical step in grounded theory data analysis to determine the key relationships between the concepts and categories. This section presents the process of refining and focusing the codes to “synthesise and explain larger segments of the data...and determine the adequacy of those codes.”<sup>325</sup> I define the core concepts to which I undertook the selective coding and then discuss each of these concepts in relation to the data.

I used second generation grounded theory and the constant comparative method as methodical as well as iterative approaches to way the data were collected and reflected upon incrementally throughout the data collection process. In this way what I learned as the researcher was fed back into the subsequent data collection and analysis. Addressing the research questions, collecting and analysing the data was cumulative and built upon the also cumulative development of knowledge. Though the constant comparative method is generally focused on data collection and analysis I also used this approach for creating personal records and the development of the archival product.

“The constant comparative method consists of weaving data collection with data analysis and analysing memos. All these activities enhance theoretical sensitivity and contribute to insight and illumination of areas that be constructing into a theory.”<sup>326</sup>

Grounded theory is described by Charmaz as “relying on emergent processes, and the researcher’s emerging constructions of concepts shape both process and product”<sup>327</sup>. As one of the key features of grounded theory the constant comparative method provides an overarching framework for reflexive practice in which

the emerging content shapes how you use the tools. Your grounded theory journey relies on interaction – emanating from your worldview, standpoints, and situations, arising in the research sites, developing between you and your data, emerging with your ideas, then returning back to the field or another field, and moving on to conversations with your discipline and substantive fields. To interact at all, we make sense of our situations, appraise what occurs in

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<sup>321</sup> Charmaz, *Constructing Grounded Theory*.

<sup>322</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*; Birks and Mills, *Grounded Theory: A Practical Guide*, 2011.

<sup>323</sup> B. G. Glaser, *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*, Advances in the Methodology of Grounded Theory (Mill Valley, CA: Sociology Press, 1978), <http://books.google.com.au/books?id=73-2AAAAIAAJ>.

<sup>324</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2011, 98.

<sup>325</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 57.

<sup>326</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015, 62.

<sup>327</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 178.



them, and draw on language and culture to create meanings and frame actions. In short, interaction is interpretive.<sup>328</sup>

It is the study which guides the data collection and requires developing processes which work within the context to understand what is most significant.<sup>329</sup>

The constant comparative method is the reflexive process that brings theoretical intent to life through practice. It is about being in the moment with the knowledge of hindsight and anticipation of what is yet to be experienced. These activities are as interfused as the human experience. By consciously using the constant comparative method I as the researcher was continuously reminded of the subjective processes of social construction which are so often camouflaged by predominant paradigms, actors or objects.

The constant comparative method is more than a way of working with data and creating new knowledge in grounded theory research. The constant comparative method requires that the researcher progressively revisit their own knowledge and assumptions – not only as they might have been but as they are being created. As a reflexive process the researcher is required to learn about herself as well as the participants. It is personal knowledge and pre-understandings which are being challenged, stretched and possibly shattered into what is simply ‘the many’. The purpose of the procedures is to make explicit what the researcher has ‘reconstructed’ from their tacit understanding of the data.<sup>330</sup>

### 3.4.5.2 Theoretical memo-writing

Theoretical memo-writing was an important analytical process and part of an ongoing activity in this grounded theory research. Memo-writing served in analysing and recording observations regarding the research data and context as well as my experience as the researcher. Memos were created through the use of words, diagrams and maps to analyse data for codes, their relationships and the theoretical implications.

Theoretical memo-writing is the capturing of “thoughts, feeling, insights and ideas in relation to a research project”.<sup>331</sup> As Birks and Mills explain, in grounded theory research memos are an integral part of making sense of the research and the experiences. Incorporating memos within the reporting of grounded theory provides insight into reflexive thinking, building concepts and practice. The researcher records their thinking and analytical processes. Memos “help build the intellectual assets” as the research progresses.<sup>332</sup> Memos in grounded theory also become data for analysis and speak of reflexivity in researcher practice.

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<sup>328</sup> Ibid., 179.

<sup>329</sup> P. Noerager Stern, “Glaserian Grounded Theory,” in *Developing Grounded Theory: The Second Generation*, ed. J. M. Morse, P. N. Stern, and J. M. Corbin (Walnut Creek, CA: Left Coast Press, 2009), 61, <http://books.google.com/books?id=7h3mlwAACAAJ>.

<sup>330</sup> R. W. Grove, “An Analysis of the Constant Comparative Method,” *International Journal of Qualitative Studies in Education* 1, no. 3 (January 1988): 273–79, doi:10.1080/0951839900030105a.

<sup>331</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2011, 40.

<sup>332</sup> Ibid., 10.

### 3.4.5.3 Practising the constant comparative method in a postmodern paradigm

In the context of this research, practicing the constant comparative method needed to reflect the inherent postmodern influences and participatory epistemology. Implementing a range of methods and techniques, as part of the constant comparative method created a mindful approach to working with people and research data.

This consideration for working with people as well as the data is of particular significance. “Guba and Lincoln call for more work that exemplifies postmodern methods and textual representations.” The researcher wants to uncover voices that may have otherwise been silenced.<sup>333</sup> For Jackson and Mazzei, the qualitative researcher working in postmodern paradigms thinks differently about “how they collect, analyze, and represent meaning using the voices of others, as well as their own. The methodological implications of this view demand that readers of this collection question what they ask of voice, question what they hear and how they hear (their own privilege and authority in listening and telling), and deconstruct why one story is told and not another.”<sup>334</sup>

Rather than following a prescribed process, as the researcher, I was guided through the context of the research.<sup>335</sup> As Denzin and Lincoln highlight, a significant part the researcher’s contribution is to establish the relevant criteria when selecting alternate methods for evaluating their work. There is an immediacy to this as well as reflexivity. It demands ‘ways’ of doing and representing appropriate to the group, individual and research needs. “Alternate methods for evaluating their work including verisimilitude, emotionality, personal responsibility, an ethic of caring, political praxis, multivoiced texts, dialogues with subjects, and so on.”<sup>336</sup>

Rather than posing master narratives and vocabularies, empirical realities are viewed as stories and narratives.<sup>337</sup> In-depth interviewing is not the only source for eliciting personal accounts.

Possessions (such as films and photos), may be used as talking points to trigger discussion with the informant. They can be examined as a means of identifying the significance of individual informants attached to them and to the events of people which they symbolise. They can be used to trigger discussion or become the centre of discussion as they enable focus on a particular set of life events.<sup>338</sup>

The progressive analysis of data influenced how and what data were collected in subsequent interviews. This second generation grounded theory process incorporated two levels of analysis; I adapted the constant comparative method as described by Charmaz to explore the

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<sup>333</sup> A. Y. Jackson and L. A. Mazzei, *Voice in Qualitative Inquiry: Challenging Conventional, Interpretive, and Critical Conceptions in Qualitative Research*, (London: Routledge, 2009), 3. Kindle Edition

<sup>334</sup> *Ibid.*, 4.

<sup>335</sup> Denzin and Lincoln, *The SAGE Handbook of Qualitative Research*.

<sup>336</sup> *Ibid.*, 9.

<sup>337</sup> Lyotard, *The Postmodern Condition: A Report on Knowledge*; Gubrium and Holstein, *The New Language of Qualitative Method*.

<sup>338</sup> V. Minichiello, R. Aroni, and T. N. Hays, *In-Depth Interviewing: Principles, Techniques, Analysis* (Melbourne, VIC: Pearson Education Australia, 2008), 140.

production of vignettes while concurrently examining the research processes. In this way I was learning not only from the data collection and analysis but also reviewing and modifying the research processes with participants in light of new knowledge. This application of the constant comparative method will be described in detail in the findings (Chapter 4).

### 3.4.6 Reflexivity

The researcher practice of reflexivity is another significant iterative process within grounded theory research. In this section I share the way in which I worked with reflexivity in this project.

Though reflexive practice is generally considered implicit in iterative enquiry, it was a conscious activity in this research while finding my way methodologically and making decisions regarding the appropriateness of the methods and techniques for working with human participants. As Dickson-Swift, James and Liamputtong explain, reflexive practice asks the researcher to be aware and explicit in the activity of thinking, feeling and sensing what is happening in the conduct of a project, and the impact of the researcher and their own subjectivity. I was challenged regarding my own subjectivity and how it was reported so that others could learn from my ‘personal’ experience.<sup>339</sup>

In this postmodern world reflexivity was a process of self-critique in the creation of meaning and knowledge which, as established in Chapter 2, were socially constructed. Rather than being overwhelmed by this complexity, Grbich emphasises the researcher’s ability to choose how they position themselves in what is a continuum of reflexivity and authority. Through the use of techniques which clearly represent the position and the perspective being described the ‘voices’ of the researcher, participants and texts are promoted to speak for themselves.<sup>340</sup>

Postmodernism confronts concepts of researcher neutrality to a world that is considered “complex and chaotic, and reality as transitional and multiply constructed.”<sup>341</sup> Positivist notions of researcher objectivity are replaced by subjectivity and an awareness of just how influenced we are by our values, beliefs and life experiences: and how these in turn frame the way we see the world, interact with people and interpret data in the research context.<sup>342</sup>

Constructivist grounded theory recognises the subjective nature of the research and the importance of reflexivity.”<sup>343</sup> As the researcher I had to ‘tune in’ and examine my own assumptions, the theoretical underpinnings which I brought to the study as well as the role I played in conducting the study and the relationships I developed with participants. Reflexivity was fundamental to this research as interpretive practice and the processes of learning and

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<sup>339</sup> V. Dickson-Swift, E. L. James, and P. Liamputtong, *Undertaking Sensitive Research in the Health and Social Sciences: Managing Boundaries, Emotions and Risks*, Cambridge Medicine (Cambridge: Cambridge University Press, 2008), 23; J. Marshall, “Self-Reflective Inquiry Practices,” in *Handbook of Action Research: The Concise Paperback Edition* (London: SAGE Publications, 2006), 335.

<sup>340</sup> C. Grbich, *Qualitative Data Analysis: An Introduction* (London: SAGE Publications, 2013).

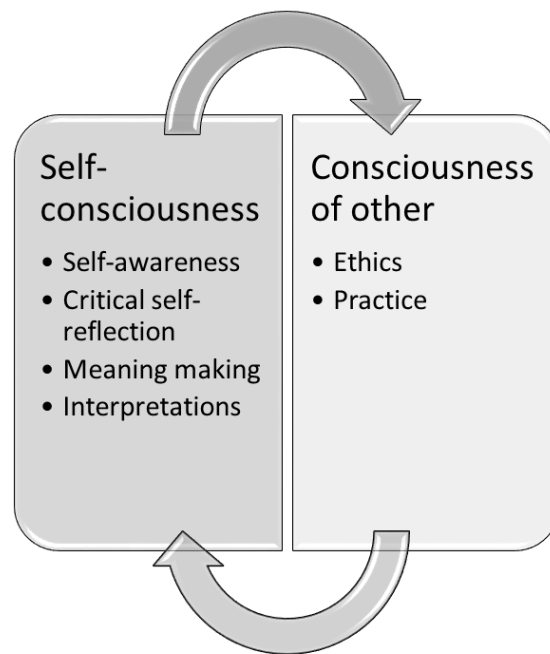
<sup>341</sup> *Ibid.*, 8.

<sup>342</sup> *Ibid.*, 113.

<sup>343</sup> *Ibid.*, 88.

problem solving which occur in qualitative research. Reflexive practice raised my sensitivity to the active part I came to play in the lives of the research participants, not only during the course of the interviews but also after the conclusion of the interviews.

Imagine a piece of music which is composed of individual and unique notes. They sound individually but in relation to each other they communicate a story, a melody or a song. The sounds when played vibrate and overlap to create harmonies or possibly discord. Reflexivity is equivalent to orchestrating the research so that it does justice to voices and respects their positions as part the research story composed and told.



**Figure 8 Reflexivity**

Figure 8 illustrates researcher reflexivity as being both conscious of self and of other; this heightened consciousness is integral to ethical practice. A reflexive approach to the process of working with people as well as their data created definition in the phases of research. Through analysing “how and why” I did things I developed reflexive practice and processes to reflect the voice of the participants as well as their situated contexts.

### **3.4.7 Open in-depth interviews and member checking**

Choosing to do in-depth interviews was founded on my own beliefs that an individual has the right to speak for him or herself when possible and in doing so validate their own experiences both in life and in the research. In this section I detail the rationale for conducting in-depth interviewing to hear participant voices in this study. I provide a breakdown of activities, undertaken as part of the weekly interviews, and conclude the section with reflections which influenced the way the interviews were conducted.

In-depth interviews were particularly suited for exploring participant's voices, their "thoughts, perceptions and feelings...studying how people attach meaning to and organise their lives, and how this in turn influences their actions".<sup>344</sup> In-depth interviewing was pivotal to the participant telling their stories and memories. It also created a forum in which those stories and the personal records being created were able to be reviewed in terms of meaning, the accuracy of the content and ease of use of the form.

In-depth interviewing was used for its capacity to elicit the participant's voice and their life as experienced by them. Even though in-depth interviewing may include the telling of life history the focus of the interviews in this research was not to tell a chronological life story. The interviews focused on what the participant chose to tell me so that we could explore the richness of those embodied experiences. "The doing of interviews is personal, interactional, and emotional. It is embodied work that can have implications for the researcher as well as the researched. How does the researcher present him- or herself? How is the interaction embodied? How are feelings presented and managed?"<sup>345</sup>

Open in-depth interviews are part of a continuum of interviewing methods which range from the highly structured interview to what is more loosely structured and conversational.<sup>346</sup> The in-depth interview is very open in its format and provides "a specific kind of interaction, in which the researcher and the interviewee produce language data about beliefs, behaviour, ways of classifying the world or about how knowledge is categorised".<sup>347</sup> By its nature it "allows the interviewee enough time to develop their own accounts of the issues important to them"<sup>348</sup>. When in-depth interviews are conducted over an extended period of time they facilitate conversations with more profound exploration of personal narratives and experiences. They can provide rich descriptions of personal and social life revealing the perceptions of the person being interviewed. In-depth interviews provide a forum for accessing unique perspectives.

Getting to know people in life and letting them get to know you takes time. In research we can be very bound by our project timeframes. Yet, exploring the perspectives of another person is difficult to comprehend in the space of one meeting.

In-depth interviewing was not an activity undertaken independently of the other methods when meeting with participants. It was a process of open and face-to-face conversations which supported the record creation activities.

- I developed a set of questions (See Appendix 3: Sample Questions) as a starting point for the first meeting with participants. These questions were intended as a guide to get

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<sup>344</sup> Minichiello, Aroni, and Hays, *In-Depth Interviewing: Principles, Techniques, Analysis*, 9.

<sup>345</sup> T. S. K. Kong, D. Mahony, and K. Plummer, "Queering the Interview," in *Handbook of Interview Research: Context and Method*, ed. J. F. Gubrium and J. A. Holstein (Thousand Oaks, CA: SAGE Publications, 2002), 250.

<sup>346</sup> Minichiello, Aroni, and Hays, *In-Depth Interviewing: Principles, Techniques, Analysis*, 47.

<sup>347</sup> J. Green and N. Thorogood, *Qualitative Methods for Health Research* (London: SAGE Publications, 2004), 87, [http://books.google.com.au/books?id=\\_b0FHJCz-\\_EC](http://books.google.com.au/books?id=_b0FHJCz-_EC).

<sup>348</sup> *Ibid.*, 80.

the conversation started rather than act as a script. They also served initially to get-to-know the participants' basic demographical and biographical information.

- For each participant the interviews ran over a period of eight weeks and consisted of weekly meetings scheduled on days and times which suited the participants and their support person. I would call the participant the day before each interview to check that they felt up to being interviewed.
- Respecting and reciprocating the hospitality was important. Each participant decided where in their home it was most comfortable for us to sit and talk. I would take a packet of biscuits to contribute to the tea/coffee I was offered upon entry to their home.
- The phases of work undertaken throughout the interviews as listed below were not planned prior to commencing the data collection. They evolved in response to each interview as it was undertaken: in seeking to problem solve and answer the research questions.

Table 4 provides an overview of the interviews weeks 1 to 8. A preliminary meeting was conducted with each of the participants and their support person where the explanatory statement and informed consent were discussed. This meeting also served to ensure that the participant was genuinely interested in being involved in the research and the attending carer understood the research process and their ethical rights throughout the course of the research.

- Determine if the potential participant understood the concepts of the research project
- Determine if the participant wished to participate in the research
- Determine the person understood the research and conditions described in informed consent
- Determine the carer/family member has understood the research process and the options informed consent.

Weeks 1 to 8 consisted of eight weekly in-depth interviews of two hour duration. The interviews were conducted in the participant's home.

**Table 4 Overview of interviews weeks 1–8**

<b>Week</b>	<b>Overview</b>	<b>Outline of activities Researcher objectives.</b>	<b>Research objectives.</b>
<b>1</b>	Getting to know the participant/ Getting to know each other.	Begin by asking generic autobiographical questions (See Appendix 3 for Sample Questions).	Use the questions as just a starting point for getting to know the person.
<b>2</b>	Understanding the participant's perception of their personal context.	Discuss and map participant's social and support network.	Explore the people and support network from the participant's perspective.
<b>3</b>	Open conversation.	Open conversation directed by participant.	Allow time for the participant to tell their own stories.
<b>4</b>	Open conversation. Take photographs of significant objects. Begin review of individual stories/vignettes (Part 1 – this process is ongoing. It was a case of reviewing in light of added stories each week).	Review of individual stories/vignettes (Part 1) (The review process was incremental as it was not possible to review all the stories in one sitting).	Are the stories sound and representative from the participant's perspective? Who would the participant be prepared to share the story with? What are the feelings and/or emotions associated with each story?
<b>5</b>	Open conversation.	Review of individual stories/vignettes (Part 2).	Are the stories sound and representative from the participant's perspective? Who would the participant be prepared to share the story with? What are the feelings and/or emotions associated with each story?
<b>6</b>	Open conversation.	Review of individual stories/vignettes (Part 3).	Are the stories sound and representative from the participant's perspective? Who would the participant be prepared to share the story with? What are the feelings and/or emotions associated with each story?
<b>7</b>	Open conversation Review of individual stories/vignettes (Final).	Review of individual stories/vignettes (Final).	Are the stories sound and representative from the participant's perspective? Who would the participant be prepared to share the story with? What are the feelings and/or emotions associated with each story?
<b>8</b>	Final meeting with participant and consignment of book of vignettes.	Consigning 'the book' to the participant.	Show respect for the contribution of the participant. Create a sense of ceremony by celebrating the 'book'. Get a sense of how the participant feels about the stories presented in their 'final' format.

For each participant the interviews totalled approximately 16 hours of audio-recording and around 160 pages of transcripts. Each two hour interview required two days of transcribing as the conversations required careful listening and comprehension. There was much repetition and the conversations were sometimes emotional or confronting.

Throughout the first weeks I transcribed that week's audio-recording so that I could review the text in preparation for the next week. Transcribing those first interviews was excellent in terms of sensitising myself to the voice, language and conversational rhythms of the participants. Transcribing was a resource intensive task due to the recorded voices of participants being very repetitive and sometimes difficult to hear or understand. Outsourcing the transcription of some audio-recordings was a pragmatic decision. While these transcriptions were being undertaken I continued to review and analyse the interviews by listening to the recordings. Those stories I transcribed became the individual vignettes and eventually composed the participant's 'life book'. Outsourcing the transcriptions freed me up to focus on the process of developing the vignettes and then studying their content and meaning.

Within those first weeks it also became evident that undertaking comparative collection and analysis of data in large quantities and with complex conversational nuances was impossible to sustain when interviews, data collection and analysis were all being done concurrently. This became even more pronounced as the representation and review of vignettes with participants was introduced in the middle weeks. This required further editing and desktop publishing.

Due to the sensitivity and the intensity of the research and getting to know participants so well over an extended period of time, these interviews were intense and required a lot of personal investment as well as attention to logistics. I needed to fit in with participant and carer availabilities. Sometimes it was not possible to schedule interviews on separate weeks so there was a substantial period of time where I was interviewing two participants a week for several weeks. The interview process needed to be modified for each person due to their personal and sometimes emotional nature. Using the comparative method for data collection and analysis meant that it was essential to undertake the activities of interviewing, transcription and analysis concurrently.

### **3.4.8 Ongoing consent: A way of doing**

Previously I identified that ethical approval for this project was gained prior to recruitment of the participants. I needed to be conscious of working ethically with participants. An important aspect of this was to develop a process of ongoing consent that could be continued throughout the research.

Ethics and informed consent were of primary concern due to the sensitive nature of the research interviews and the possible vulnerability of participants with dementia. Meeting the requirements of Monash Human Ethics was both an institutional requirement and a process for determining the integrity of the research and protecting the participants involved. The National Statement of Ethical Conduct (NHMRC) in Human Research describes in depth the range of ethical and design considerations of doing research including qualitative methods in



the field.<sup>349</sup> Anna Freud's dictum was to "Do the least harm".<sup>350</sup> Human ethics cautions to do no harm.<sup>351</sup> I was challenged to consider how I could do 'good' in the context of research by facilitating an affirming participant experience.

It was of the utmost importance that information be communicated clearly, progressing through each section and confirming comprehension at each step of the way rather than at the end. Two versions of the explanatory statement and informed consent were conducted; one each for the participant, the family member or carer and other people who contributed to the interviews when solicited by the participant. Informed consent became part of an ongoing decision-making process undertaken throughout the course of the interviews.

The process of gaining informed consent was conducted at a preliminary meeting of approximately 45 minutes duration, rather than being scheduled as one of the interviews. This was the opportunity to meet with each participant to ascertain their desire to be involved as well as their comprehension of the research and what it would mean to be interviewed. No documentation or audio-recordings of these preliminary meetings were undertaken. This type of data collection was only begun once the participant had been informed and had consented.

During the preliminary meeting I explained the research project, the purpose of the research and how the findings would be disseminated. As well as providing a printed copy of the explanatory statement I read the statement out loud to the participant and the family member or carers who were present as witnesses. Each section was read out loud and then discussed with the participant to determine if we had a common understanding of what had been said or if there were any questions that needed to be answered. The participant completed the informed consent form by agreeing or disagreeing to the individual options listed indicating to what extent they wished to participate. I reinforced the fact that participation was completely voluntary and that it was possible to cease participation completely or discontinue an interview/conversation at any point. Recommencement of the interrupted interviews would be at the discretion of the participant.

Although the participant had signed the informed consent, their consent in the subsequent interviews was not assumed. At commencement of the first and second interview I reiterated what the project was about and asked the participant if he/she was still 'happy' to be involved. I called the participant the day prior to the scheduled interview to confirm that he/she felt up to meeting. If I arrived at the participant's home and they did not feel up to being interviewed I rescheduled for another time or we postponed to the next week. At each point of the interview process consent meant determining what the participant felt comfortable doing and sharing. Participants were encouraged to stop or take a break when necessary.

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<sup>349</sup> National Health and Medical Research Council, "National Statement on Ethical Conduct in Human Research" (Canberra, ACT: NHMRC, 2007).

<sup>350</sup> Anna Freud as cited in P. Thomson and M. Walker, *The Routledge Doctoral Student's Companion: Getting to Grips with Research in Education and the Social Sciences* (Abingdon, OX: Taylor & Francis, 2010).

<sup>351</sup> National Health and Medical Research Council, "National Statement on Ethical Conduct in Human Research."

Reflecting on this process and the other ethical aspects of this study including reflexivity and wayfinding have led me to conclude that these are core activities of postmodern ethical research. Later in my thesis I discuss the aspects in more depth.

### 3.4.9 Sharing and representing stories: Vignettes, photographs

The creation of vignettes was in response to the need for working ethically, and developing a research process suited to interviewing the person with dementia. Vignettes were created and used in this study as a technique for exploring the personal stories, events, actions and context for the participants. These vignettes represented those rich pockets of data that Miles and Huberman write about when they say “Not all data are equal. During early data collection, as a researcher becomes more familiar with how things work with the case at hand, he or she often finds rich ‘pockets’ of especially representative, meaningful data...that can be pulled together in a focused way for interim understanding.” These are data subsets and may be collected over a period of time. “Vignettes offer an opportunity to engage study participants actively in producing, reflecting on, and learning from the data.” The use of the term ‘vignette’ in qualitative research is mostly associated with the construction of “a focused description of a series of events taken to be representative, typical, or emblematic in the case” being studied.<sup>352</sup>

In qualitative research the term vignette has several meanings and purposes depending on the context of their use. Vignettes are short scenarios which may be hypothetical or real; they may be “used in conjunction with other forms of data collection to obtain more information about respondents” and to elicit responses from participants. “One aspect of the vignette is that it is like a photo with blurred boundaries or a description that shades off at the edges. In data presentation, vignettes are usually small, illustrative stories involving observation of activity and behaviour, which illuminate or trouble some important aspect of the area of investigation.”<sup>353</sup> In qualitative data analysis vignettes also describe the parts of the data which are exemplars of the data being studied.<sup>354</sup> The use of vignettes provides a useful technique for exploring contexts which may be sensitive in a way that allows “participants to define the situation in their own terms.”<sup>355</sup>

I needed to determine the most appropriate methods for analysing the data collected, throughout the interviews, for the stories and content of the personal records. I required a form for representing and reviewing those stories in ‘manageable chunks’. These vignettes evolved through the process of seeing how much of a participant’s story in text would fit printed on a page. These vignettes supported the narratives being told through their relationship to the other stories. They also needed to represent the language as used in the story as it was told. The story’s text was used as transcribed with minimal editing. Repeated words or phrases were removed for the purpose of the vignette to make the story legible and

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<sup>352</sup> M. B. Miles and A. M. Huberman, *Qualitative Data Analysis: An Expanded Sourcebook* (Thousand Oaks, CA: SAGE Publications, 1994), 81.

<sup>353</sup> Grbich, *New Approaches in Social Research*, 18.

<sup>354</sup> R. L. Miller and J. D. Brewer, eds., “Vignette,” in *The A–Z of Social Research* (London: SAGE Publications, 2003), 2.

<sup>355</sup> C. Barter and E. Renold, “The Use of Vignettes in Qualitative Research,” *Social Research Update* 25, (1999), 1, <http://sru.soc.surrey.ac.uk/SRU25.html>.

cohesive when reread. The size of the font proved important as did the need to associate a photograph with many of the vignettes. The final set of vignettes using the participant's own words and 'voice' with supporting images formed what I called a 'life book'. The life book is a collection of those stories told and retold throughout the interview process.

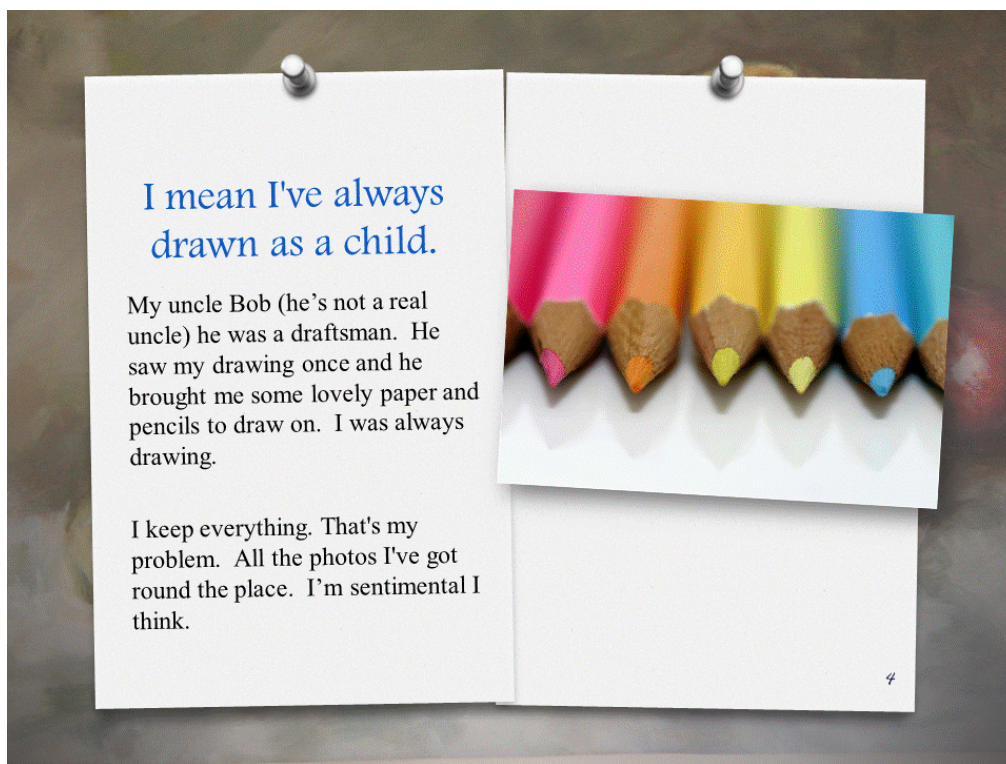
The stories in the form of vignettes and images were edited and formatted, into what I describe as a life book, so that they could be easily read by the participant taking into account any special physical needs. This required:

- Adjusting the quantity and quality of content
- Maintaining the language and voice of the participant rather than rewriting the content
  - The vignettes were edited to remove repetition and to allow the stories to be read easily
- Ensuring there was sufficient quality in the stories represented
- Ensuring the size of text on the page was legible for each participant
- Managing the number of stories and pages to a number that could be read in one sitting without being overwhelmed.

Each page of content in the book was reviewed by the participant as part of the interview process for:

- Accuracy of content
- Quality and relevance to self
- Personal meaning: descriptive metadata
- Who they would be happy for the stories to be shared with: family, friends, carers outside family, not at all, or only under certain circumstances.

The outcome of this process consisted of approximately 60 pages of vignettes. This was printed and bound into a book which was presented to the participant in the final interview. They were also provided with the book in a digital form. The vignettes were analysed and coded. The vignettes became an important tool and an explicit data set of person-centred records; they were reviewed with the participant as well as a set of data for further study. Using thematic analysis selected participant's transcribed stories were put into the format of a PowerPoint document (see Figure 9).



**Figure 9 Example of customised PowerPoint template**

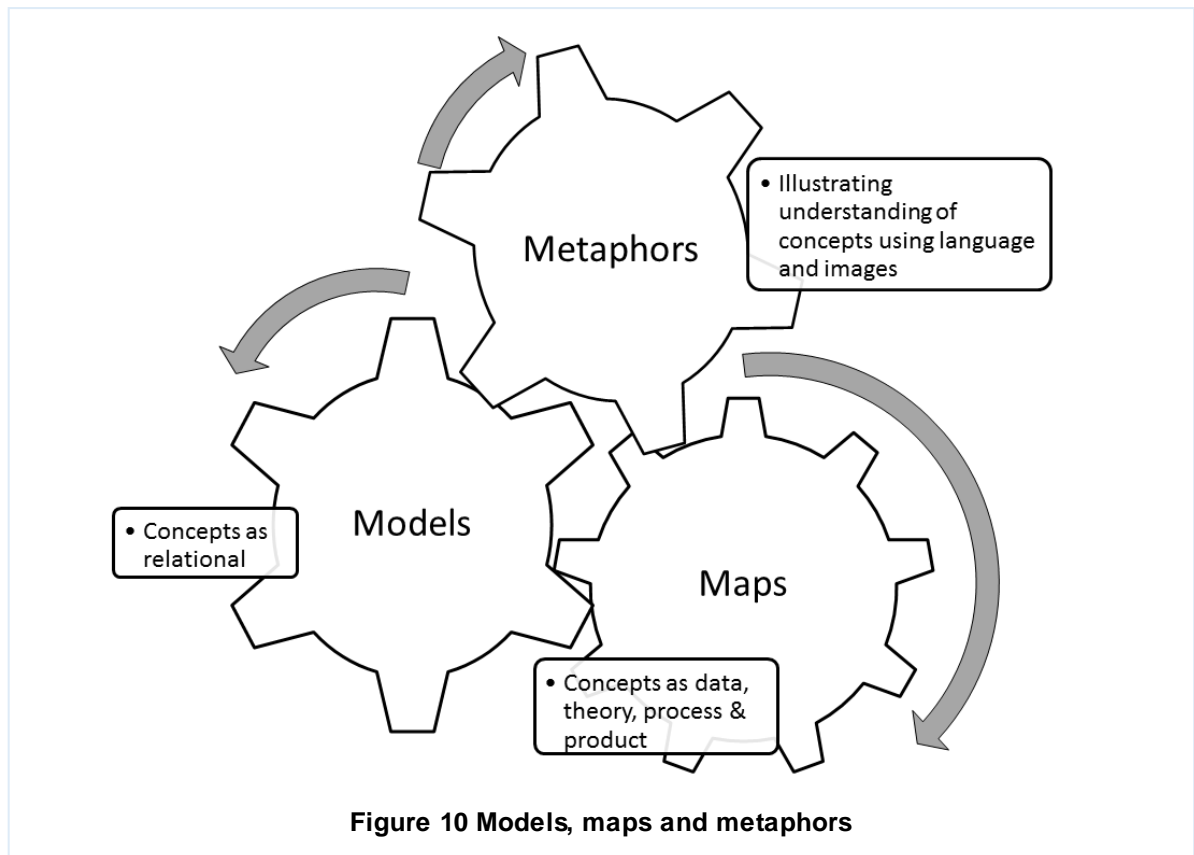
Participants were provided with narrative excerpts from the transcripts and the archival material for review. Each PowerPoint template background was adapted with an image drawn from the items described by the participant to have personal significance. These vignettes, and their specific use within this research, are discussed in the findings in Chapters 4, 5 and 6. The ‘life book’ became a tangible product for further analysis as well as discussion and review.

### **3.4.10 Models, maps and metaphors**

In working with complexity and plurality there was a need to examine diverse perspectives contemporaneously, i.e. the personal and more situated contexts against their broader contexts and positioning. I therefore developed multiple ways of achieving this implementing models, maps and metaphors. Models, mapping, and metaphors were techniques for analysing data and illustrating concepts and their relationships to each other (see Figure 10). Concepts and our understanding of these, whether conscious or not, are implicated in the way we perceive the world. Concepts are also highly “metaphorical in nature” and embedded in everyday language, thought and action.<sup>356</sup> The use of metaphors as “the ability to see something as something else” is described by Fichtner as an important learning tool for modelling ideas. As meaning is contextual, so too were these representations of concepts explored in this research, which were so closely associated to culture, values and world views.<sup>357</sup>

<sup>356</sup> G. Lakoff and M. Johnson, *Metaphors We Live By* (Chicago, IL: University of Chicago Press, 2008).

<sup>357</sup> B. Fichtner, “Metaphor and Learning Activity,” in *Perspectives on Activity Theory*, ed. Y. Engeström, R. Miettinen, and R. L. Punamäki-Gitai (Cambridge: Cambridge University Press, 1999), 314.



Clarke describes situational analysis as a powerful mapping technique in pushing grounded theory around the postmodern turn by creating a new approach to analysis. This approach to analysis has, according to Clarke, extended Strauss's situation-centred "social worlds/arenas/negotiations" framework built on the action-centred "basic social process" concept. Situational analysis creates a framework which encourages the use of mixed media, cartographic approaches to working with a range of data that includes "major human, nonhuman, discursive, and other elements in the research situation of inquiry and provoke analysis of relations among them."<sup>358</sup> In situational analysis mapping is an analytical exercise in which the "situation per se becomes the ultimate unit of analysis, and understanding its elements and their relations is the primary goal.

Mapping was used in a range of analytic activities within the research and this data was used to create conceptual models and representations. Mapping as described by Clarke is a process of inclusion, so I was able to bring together diverse levels and categories of concepts. Table 5 explicates the ways in which models, maps and metaphors were used in this research.

<sup>358</sup> Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*, xxi–xxii.

**Table 5 The use of models, maps and metaphors in this research**

<b>Mapping was particularly useful in working across levels of analysis.</b>	<ul style="list-style-type: none"> <li>• Mapping was used to tease out and make sense of the concepts being described in the archival literature after open coding of the text.</li> <li>• Extensive stakeholder engagement was mapped to analyse not only the activity I had undertaken but to develop learning from the processes and the outcomes.</li> <li>• Aspects of the research process and the participant data were recorded and organised using mapping in preparation for further analysis and reporting.</li> <li>• Core literature was analysed and mapped to explore the key concepts and associated discourses. (See Appendix 6 for examples of this analysis process) <ul style="list-style-type: none"> <li>○ I used coding to tease out relevant individual concepts. It was a valuable experience as it allowed me to map out the concepts and their relationships in intricate detail and provides a tool for positioning my research within archival frameworks. In comparing these with the findings from the interviews, the outcomes of the mapping enabled me to address the research question.</li> </ul> </li> </ul>
<b>Modelling was used to define high level concepts in their relationships to each other.</b>	<ul style="list-style-type: none"> <li>• Models were developed to illustrate the processes I undertook in the research.</li> <li>• Models also provided a powerful way to synthesise the theory developed through analysis of findings.</li> </ul>
<b>Metaphors were used to communicate the characteristics that two seemingly different concepts may actually have in common.</b>	<ul style="list-style-type: none"> <li>• Metaphors were used in this thesis as a way of illustrating sometimes complex or abstract concepts in alternative ways.</li> <li>• Some of the images I used in developing models and drawings were metaphoric in that visually they communicate another layer of symbolism and meaning to the linguistic content.</li> </ul>

In this research, the linguistic and visual properties of mapping, modelling and metaphors were exploited to develop and explore relationships, meanings and understandings within these situated contexts. These methods were used in response to working with concepts and data in their complexity. They proved to be sensitive to the interpretive qualities of second generation grounded theory research; allowing me to work iteratively in the myriad of ways in which concepts, information and data can be perceived. They also created tangible if subjective propositions for representing the resulting processes, theory and practice.

### **3.5 Supporting the Researcher: Supporting the Researched**

This research has involved in-depth interviews with people who have early stage dementia who are dealing with associated stigma and changes in personal contexts. The nature of the interviews was focused on the personal stories that are meaningful for the person. This type

of discussion brings to the fore strong memories and emotions, sometimes of very traumatic events.

The interview process required my immersion in the lives of the research participants and their families. Many times it has proved confronting to observe and feel the stressors that coping with dementia places on already vulnerable individuals. The same researcher empathy that has facilitated effective interviews and supported the researcher-participant relationship also created an emotional load which required its own debriefing. Often the perceived events and dynamics took time and energy to put into perspective and hence it required a process separate to that of analysing the collected data.

The choice of supervisors was strategic in terms of doctoral expertise and guidance. The sensitive nature of my interactions with participants and their families left me with a need to be able to productively debrief and reflect upon the work that I was doing. I explored my options and decided that I needed a mentor or expert familiar with the needs of people with dementia. I consulted with Alzheimer's Australia and others in my network to find an appropriate person who was philosophically sensitive to the research and my approach.

On consultation with my supervisory team and Alzheimer's Australia, clinical supervision was identified as a need. This need for this type of support has been identified in other research contexts. The provision of clinical supervision to students and practitioners is both a standard and best practice in the disciplines of social work, psychology and health care.<sup>359</sup> It is a role quite separate from that of the PhD supervisor and is conducted by professionals who have appropriate qualifications. It is considered to be an essential part of articulating the relationship between the theory and practice in the development of professional knowledge. It supports researchers working in a range of fields which are very sensitive with vulnerable populations. In the discipline of information technology, where research is continuously being extended into practice areas, identifying the need for clinical supervision is about addressing the special needs of researchers in terms of physical and psychological health. This correlates with global research challenges and raises the need to support those who are working in the field.

The clinical supervisor provided the following kind of support: debriefing, solution focused discussion, and learning more about the nature and context of living with dementia. The clinical supervision has served the purpose of helping me to learn and develop expertise through the experience of the interviews. It has ensured that the needs of the participants, who are in vulnerable positions, are fully understood and respected. It has also addressed my own needs as an ethical researcher and enabled me to cope with difficult situations in ways that minimised the risks for the participants and to me as the researcher.

An important part of the post-interview phase was to dedicate time to sharing some of my experience and build it constructively into the thesis where possible. Some of the debriefing

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<sup>359</sup> D. L. Milne et al., "Evidence-Based Training for Clinical Supervisors: A Systematic Review of 11 Controlled Studies," *The Clinical Supervisor* 30, no. 1 (2011): 53–71.

was done through discussion with supervisors and my clinical supervisor as a way of realising the intensity and stepping back to be able to effectively analyse and write a thesis.

### 3.5.1 Risk management

A requirement for completing the Monash Human Ethics application was defining the process of risk management for both the participant and myself. A Monash University Risk Assessment was completed as per the Monash Occupational Health and Safety Guidelines. In order to mitigate risks for the participant, a condition for participating in the research was stipulated that a family member or carer needed to be present in the home during the interviews as support in case the need should arise. They did not need to be present throughout the whole interview but they did need to be in the residence throughout the scheduled time. A register of scheduled appointments with location and contact details was maintained. A text message was sent to one of my PhD supervisors and my husband when I arrived at the interviewee's residence and when I had left, to confirm that I had arrived and departed safely.

### 3.5.2 Technology

Developing new technology was clearly outside the scope of this research. A strategy of utilising existing technologies was adopted to see whether tools already existed to meet the needs of the research and in working with participants. Of the technology that was already available or being developed, many in line with the range of smart phones and tablets being released, were there any with the characteristics that lent them to this research?

**Table 6 Equipment used in phases of the research**

<b>Core equipment/technology/tools</b>	<ul style="list-style-type: none"> <li>• Laptop computer</li> <li>• Software: <ul style="list-style-type: none"> <li>○ Microsoft: Word, PowerPoint</li> <li>○ MindManager for conceptual mapping</li> <li>○ Digital stylus for digital drawing</li> <li>○ Bibliographic tool: Zotero.</li> </ul> </li> </ul>
<b>Phase: Scoping the research &amp; developing the research proposal</b>	<ul style="list-style-type: none"> <li>• iPhone 3 (as a conceptual model for interfaces)</li> </ul>
<b>Phase: Stakeholder engagement</b>	<ul style="list-style-type: none"> <li>• MindManager mind mapping software</li> <li>• Printed brochures &amp; business cards</li> <li>• PowerPoint for presentations.</li> </ul>
<b>Phase: The research design</b>	<ul style="list-style-type: none"> <li>• NVivo – literature review</li> <li>• MindManager – Mind mapping software.</li> </ul>
<b>Phase: Participant data collection and analysis</b>	<ul style="list-style-type: none"> <li>• Digital Dictaphone</li> <li>• DSLR Camera</li> <li>• Equipment: tripod, microphone</li> <li>• Mindmapping software</li> <li>• Butcher's paper and coloured markers</li> <li>• PowerPoint for creating vignettes <ul style="list-style-type: none"> <li>○ Printed versions of the vignettes.</li> </ul> </li> </ul>



It would need to function as an archival repository for the participant and allow me as the researcher to access and use the data collected. Though the available technology was innovative it was not always simple or easy to use. Mobile technology can still be difficult to type or write on effectively. The collected data proved to be difficult to access from the database at the back end of the technology. Even though apps created files for the photos or text there was not sufficient relational metadata to support working with these outside of the app for analysis purposes. I have listed the technology implemented within phases of the research in Table 6.

The range of software applications I tried all had attractive features, but I would have been constrained to what the application would let me do rather than explore the potential of record creation in a digital environment, even if this was in theory. I selected the technology suited to particular phases of the research. When working with participants, the technology needed to facilitate both co-creating records which could be shared and managed. I also needed to be able to analyse these records as data.

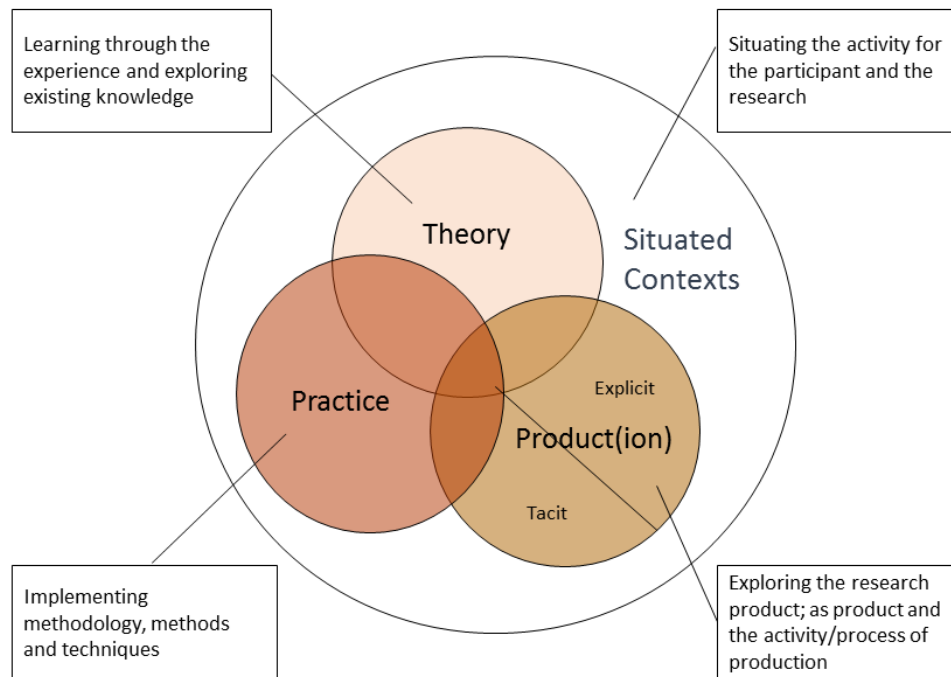
### **3.6 A Research Framework: Outcomes of this Study**

In the previous sections of this chapter I have highlighted the philosophic principles of this study, the theoretical tenets and philosophic framing of second generation grounded theory and the processes that I implemented while undertaking this study. I now provide an illustrative framework, which evolved through the work itself and reflexive learning. Examples of the research outcomes associated with this framework and its key component are identified.

The activities in this research were not geared solely towards studying the record. The study focused on understanding the interrelated components of the research process as a continuum of activities. In my role as a researcher and personal archivist I engaged in the process of co-creating records from the point before the record's inception. Figure 11 represents the four key elements I identified through reflexive analysis of this research process: situated contexts, theory, practice and product(ion). These concepts are not separate but rather integrated parts of the whole. As such these components form a holistic framework for conducting applied research. In Table 7 I demonstrate how I returned to this framework in order to identify the outcomes of this research in relationship to each of the elements. Below I give examples of how the key components of the framework were applied in this research context.

I carefully considered the semantics of the terms used in conceptualising this applied research process, and how these concepts were represented in relation to each other. The Venn diagram in Figure 11 is positioned completely within the situated contexts. The terms are defined within the drawing itself as situated activities and processes for working with applied research context. The concept of *product* is of particular interest; dictionary definitions emphasised that a product is the outcome of a process which has attributes which are not only physical or explicit in nature; a product has tacit meaning as well.

A good, idea, method, information, object or service created as a result of a process and serves a need or satisfies a want. It has a combination of tangible and intangible attributes (benefits, features, functions, uses) that a seller offers a buyer for purchase. For example a seller of a toothbrush not only offers the physical product but also the idea that the consumer will be improving the health of their teeth.<sup>360</sup>



**Figure 11 Applied research process**

<sup>360</sup> "What Is a Product? Definition and Meaning," *BusinessDictionary.com*, accessed March 1, 2016, <http://www.businessdictionary.com/definition/product.html>.

**Table 7 Examples of research outcomes**

Key components	Examples
<b>Situated Contexts</b> was about situating the research activity for the participant and the research.	<ul style="list-style-type: none"> <li>• Explored co-creating person-centred records in a real life context to understand its meaning and its significance.</li> <li>• Conducted in-depth interviews with people with early stage dementia for whom memories and remembering have special significance.</li> <li>• Conducted the interviews in the participant's home - a place that is comfortable and meaningful for the participant.</li> <li>• Considered the purpose and use of the archival activity in this situated context.</li> </ul>
<b>Reflexive Practice</b> was a process of integrating the steps undertaken in the archival methods and record/archival creation.	<ul style="list-style-type: none"> <li>• Protected the participant from harm by finding ways to make their participation a positive experience.</li> <li>• Conducted interviews in the participant's home where they were in a familiar environment and surrounded by their own belongings.</li> <li>• Developed respectful relationships with participants and their families. <ul style="list-style-type: none"> <li>◦ I didn't want them to feel that I was taking their hospitality for granted.</li> </ul> </li> <li>• Selected and developed a range of methods and techniques according to the context and type of information or data.</li> <li>• Reviewed the vignettes with participants as a work-in-progress.</li> <li>• Consciously worked to level the roles between researcher and participant.</li> </ul>
<b>Product(ion)</b> (Tacit/Explicit) is about the activity of creating the archival product; it is product and its production.	<ul style="list-style-type: none"> <li>• Explored the co-created vignettes as a human activity as well as records with multiple dimensions and representations over a period of several weeks.</li> <li>• Inquired as to what the record was in this situated context, both tacit and explicit as well as aesthetic, theoretical, linguistic and visual.</li> <li>• Created the archival product as an aesthetic as well as linguistic representation of the vignettes.</li> <li>• Created the archival product to accommodate participant's disability i.e. larger font.</li> <li>• Created photographs/visual representations where possible as part of the vignettes.</li> <li>• Explored meaning of the memories and vignettes for the participant.</li> </ul>
<b>Theory</b> is about learning through experience and existing knowledge which helps understand what is happening and why and then what to do next.	<ul style="list-style-type: none"> <li>• Reviewed the vignettes and their creation reflecting on what I learned.</li> <li>• Explored the theory that reflected the experience, processes and products as they arose and in order to learn 'on the go' implementing and reflect on what I was learning.</li> <li>• Developed my knowledge of informed consent in theory and practice.</li> <li>• Explored the theoretical significance of the 'meaning' participants associated with personhood, memory and identity.</li> </ul>

In this research context, I was working in complex and sensitive spaces in which not all was explicit and the trace was like the spark which *may* fire a flame. Events occurred. What was it that inspired the inscribing of the trace? Choices were made: sometimes conscious and sometimes not. In studying this complex space as a phenomenon I deliberated over the details of this applied archival research process so that it could be considered as holistic perspectives.

### **3.7 Conclusion: A Responsive Approach to the Applied Archival Research Process**

In this chapter I discussed the rationale and designing of a second generation grounded theory approach, guided by the work of second generation and constructivist grounded theorists, Charmaz, Clarke and Urquhart.<sup>361</sup> I explained the ways in which the methodology fits with the principles of records continuum thinking. Addressing the research aims and situated contexts of this research required a range of tools and techniques for exploring the richness of the record as interpersonal as well as information processes and products.

It was crucial that the research processes be simple, sustainable and accommodating the individual needs of the person whose records were being studied. Prior to conducting the participant interviews I imagined many ways in which personal records might be created in terms of technology and techniques. I was continuously considering the context of the person with dementia. Each person was different. How a person is affected by dementia is unique to that person and may change from one day to the next. And we all have preferences in the way we communicate. The methodology, methods and techniques were part of innovative repertoire of processes and practice through which I addressed the needs of people as well as the research data.

Working as an interpretive bricoleur and using methodological wayfinding described in Section 3.3.1, I developed a second generation grounded theory approach which respected the sensitive context of the person with early stage dementia and fit the purpose of archival research in exploring the co-creation of person-centred records. The implementation represents intent with regard to how I worked with people and data. It was a conscious decision to distinguish discretely the needs of people who participated in the research, and how I met the research objectives. I considered equally the aspects of the situated contexts, underpinning theories, my practice as a researcher and the study of records for each of the participants and in relation to the research.

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<sup>361</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*; Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*; Urquhart, *Grounded Theory for Qualitative Research: A Practical Guide*.

## 4 Findings 1: Innovation in Working with People and their Data

### 4.1 *Introduction*

This chapter is the first of three chapters in which the results of the grounded theory study are presented. In this chapter the findings are presented in relationship to co-creating person-centred records for each of the participants in the study. The purpose of this second generation grounded theory approach to the study of records was to seek new knowledge regarding the nature of records which could support memory, identity and personhood. I sought to understand what personal records were for the participants in this research and importantly what was it that made these records personal.

This chapter presents the findings regarding innovation while working with people and their data. Particular attention is paid to revealing the processes of shared memory-making and co-creating records, and the ways in which the participants' personal and situated contexts were engaged with and understood during these archival and grounded theorising processes. Further attention is directed to the methods and techniques which were evolved and adapted to both the methodological and archival contexts of co-creating person-centred records with each participant. This is followed by an account of the archival processes that were developed to co-create vignettes and life books as personal records with the participants. This discussion explicates innovation in the practices of archival research through the combination of grounded theory and person-centred ways of co-creating the personal records with the participants.

- Section 4.2: Outlines the systematic processes for interviewing participants and generating and analysing data.
- Section 4.3: Introduces the participants in this research and their unique contexts.
- Section 4.4: The first two weeks of interviews are described with respect to the techniques implemented in exploring personal contexts with participants.
- Section 4.5: The findings are discussed in relation to personal storytelling, as a means for understanding the unique perspectives of participants and their relationship to personal records.
- Section 4.6: Weeks three to eight of the interviews are described with a focus on the processes for co-creating and reviewing vignettes.
- Section 4.7: I reflect on the concept and practice of ethical wayfinding which emerged through methodological wayfinding (described in Chapter 3), and the implications for making decisions when working with participants and their data.

### 4.2 *Studying Unique Experiences and Personal Records*

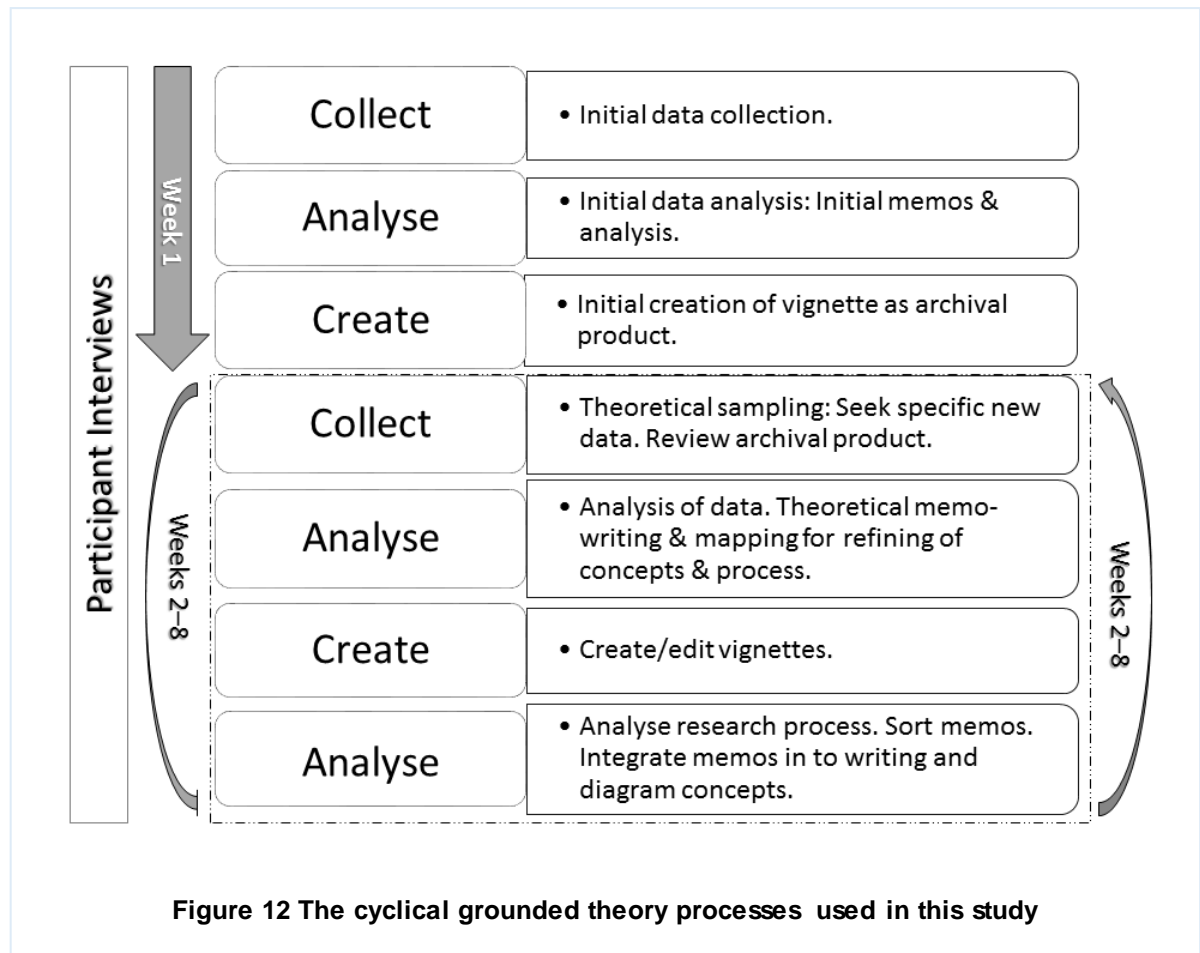
While the methodology and practice of the research were explained in the previous chapter, in this section of Chapter 4 it is important to reveal in greater depth the relationship between

methods of data collection in working with archival processes and engaging with the participants. This is significant, as it the mechanism by which the archival processes and practices for generating the person-centred record were developed, evolved and achieved. It is also central to good second generation grounded theory process that these interactive activities between preparation, action and findings are made explicit. In order to make this succinct and clear in this chapter, it is important that in Section 4.2, I provide an overview of those systematic processes and the structure of data collection and analysis that occurred to achieve the results. This process consisted of the three key sets of techniques and methods. The following are discussed in this section:

- Cyclical processes and methods for getting to know participants and their situated contexts
- Researcher processes for exploring personal data and perspectives during and after the interviews
- Techniques for incremental coding and theory building.

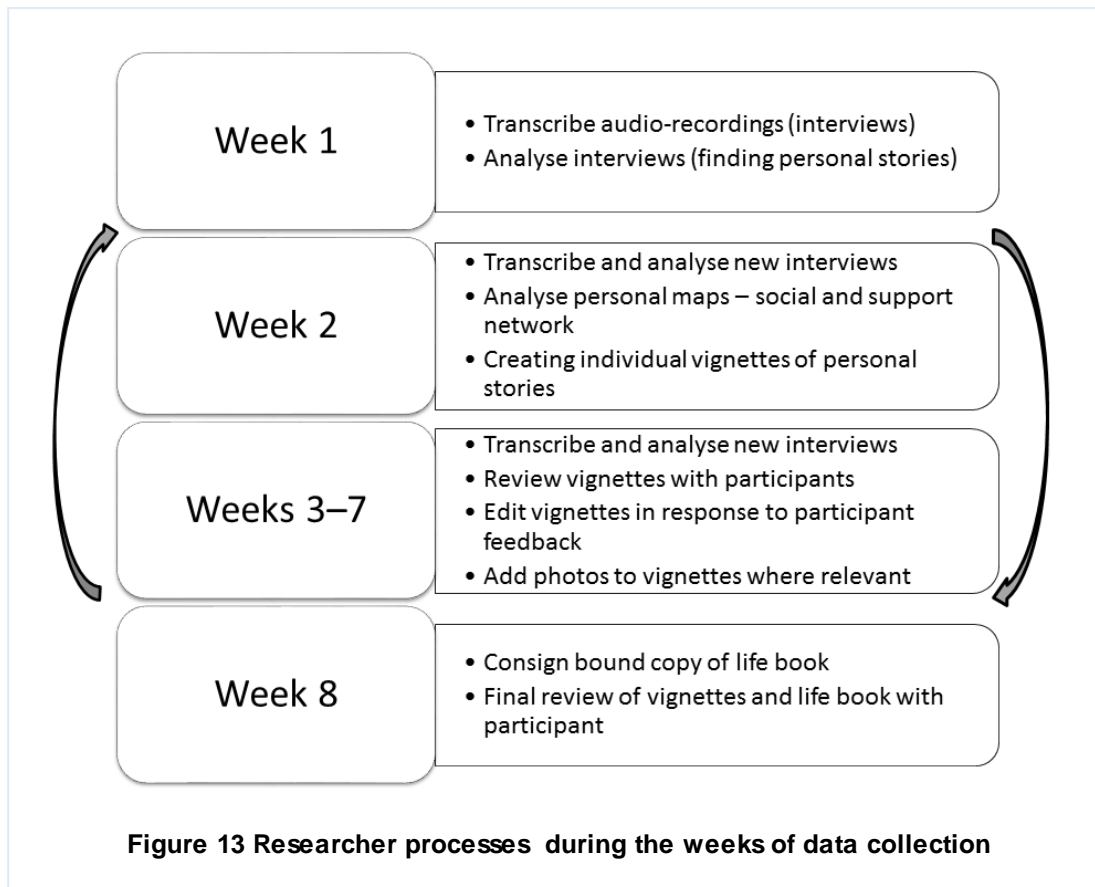
The material in this section extends and complements work already presented in Chapters 2 and 3.

Cyclical grounded theory processes were generated and used in this study as a strategy for getting to know the participants in their situated contexts. These were iterative processes undertaken through weeks 1–8 of the interviews. They are identified in Figure 12 which articulates how the use of two major cycles occurred. Cycle 1 (week 1) involved collecting and analysing data, and the early creation of archival products. Cycle 2 was a much longer and detailed process. The cycle was repeated each week for seven weeks (weeks 2–8); the details are in Figure 12. Specific archival and data collection methods included open interviews and photography.



While using these iterative cycles to collect and analyse data and co-create the vignettes there were additional specific activities that I undertook as a researcher and archivist. These archival and research processes are detailed in Figure 13. In the figure I reveal how these activities were repeated or evolved over weeks 1–8.

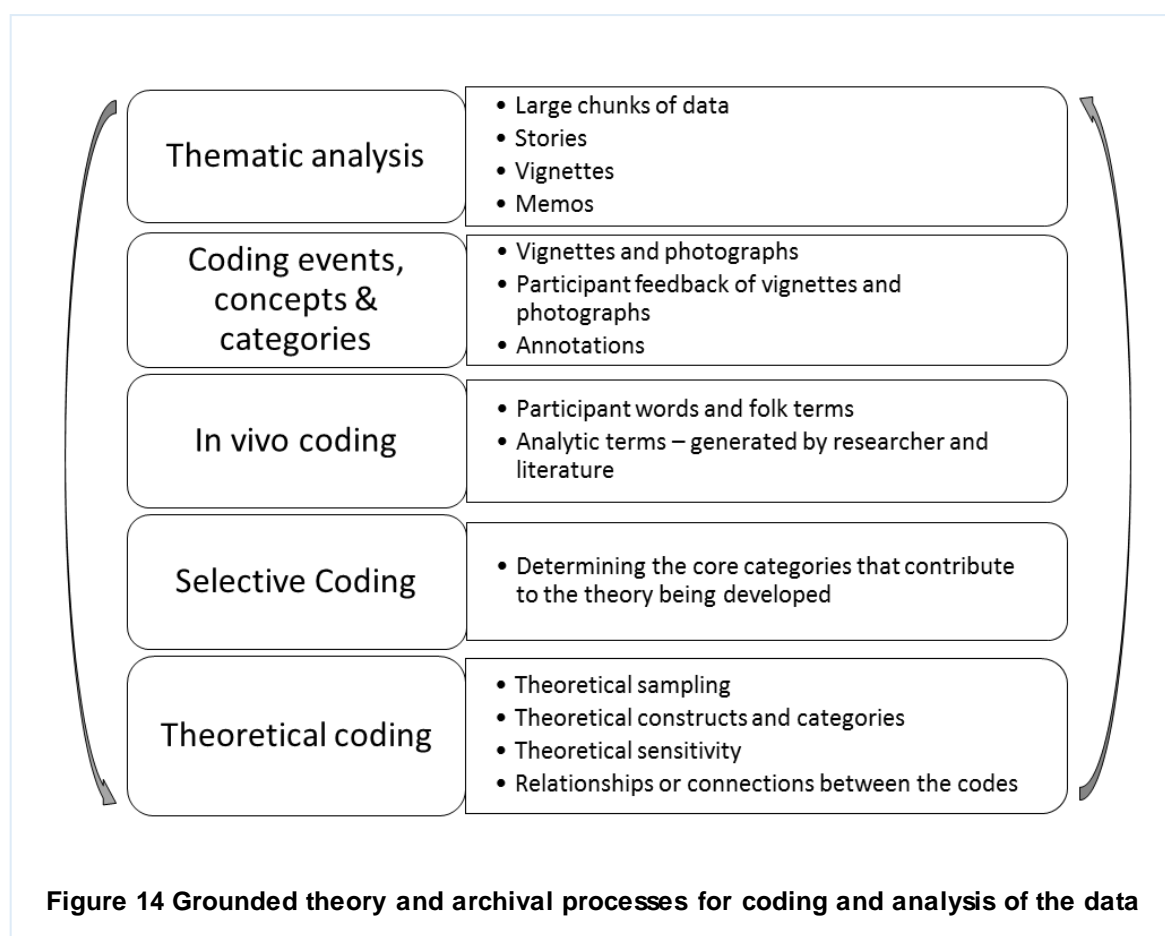
These were techniques for exploring personal data and perspectives, which were used during and after the interviews. I undertook specific research methods which supported record co-creation activities including: evolving the data interpretations, methods of sorting, and concurrent analysis while collecting new data. These methods also included personal mapping (Interview week 2) and reviewing vignettes (Interviews weeks 3–8).



Coding and theory building were core and concurrent activities undertaken during and after data collection. In Figure 14 I reiterate the array of grounded theory and archival processes described in Chapter 3, Figure 7 for coding and analysis of data from.

Various grounded theory techniques for analysing participant data (both collected and co-created) were implemented for incremental coding and theory building during the interviews (weeks 1–8) and afterwards. Grounded theory methods were combined with record co-creation processes. The main grounded theory processes of coding used were open coding for concepts and categories, selective coding for analytic theorising, and theoretical coding for grounded theory building about the personal record. Qualitative research techniques of thematic analysis and in vivo coding were also used.





It really important to acknowledge that the methods identified in Figures 12, 13 and 14 were all concurrent activities undertaken as the data were collected and analysed. Together these activities enabled the development of new methods, the achievement of rich data and findings and the fulfilment of the research aim of generating a theory of the person-centred record. The three results chapters (Chapters 4, 5 and 6) each provide different lenses and perspectives on how these aspects were used interactively and dynamically to achieve the research outcomes.

This section has explained the framework that was used for these grounded theory and archival processes to achieve the aim of the research. Particular attention was paid to processes associated with interviewing participants, generating and analysing data. In the next section, the people who participated in this research are introduced.

### 4.3 *Introducing the Participants in this Research*

The people who participated in this research were central to the project. In this section I introduce each of the participants, share some aspects of their lives and contexts, and highlight some of their unique experiences. Table 8 lists the participants' pseudonyms, their professions, ages at the time of the interview and the age at which they were diagnosed with dementia. Pseudonyms were chosen, rather than a participant code, to protect each participant's identity and as a way of respecting their personhood. The referenced data and findings are made confidential in the reporting. Associating a name was a respectful reminder that the accounts are of real people.

**Table 8 Participant pseudonym, profession and age of diagnosis with dementia**

Participant Pseudonym	Profession	Age at time of interview (2011—2012)	Age at time of dementia diagnosis
1 (Patrick)	Carpenter	62 year old man	Late 50s
2 (Karl)	Accountant	80 year old man	Mid 70s (2008)
3 (Jean)	Secretary	77 year old woman	Early 70s (2009)-

Table 9 provides an overview of the interview schedule, listing for each participant the people who actively participated in the conversations or were present in the home but not participating.

**Table 9 Overview of participants in this research**

Week	Patrick		Karl		Jean	
	Participated in conversations	Present in home but did not participate in conversations	Participated in conversations	Present in home but did not participate in conversations	Participated in conversations	Present in home but did not participate in conversations
<b>Preliminary Meeting for (Explanatory Statement, Informed Consent)</b>	1. Patrick 2. Ruth (wife)		1. Karl 2. Mary (wife)		1. Jean 2. Daughter	
<b>Week1</b>	1. Patrick 2. Ruth (wife)		1. Karl	Mary (wife)	1. Jean 2. Daughter	
<b>Week2</b>	1. Patrick 2. Ruth (wife)		1. Karl	Mary (wife)	2. Jean	Son-in-law
<b>Week3</b>	1. Patrick 2. Ruth (wife) for second hour	Ruth(wife) for first hour	1. Karl	Mary (wife)	1. Jean	Son-in-law
<b>Week4</b>	1. Patrick 2. Ruth (wife)		1. Karl	Mary (wife)	2. Jean	Grand-daughter
<b>Week5</b>	1. Patrick 2. Ruth (wife)		1. Karl	Mary (wife)	1. Jean 2. Daughter-in-law	
<b>Week6</b>	1. Patrick 2. Ruth (wife)		1. Karl	Mary (wife)	1. Jean 2. Daughter-in-law for the second hour	Son-in-law for the first hour
<b>Week7</b>	1. Patrick 2. Ruth (wife) 3. Friend		1. Karl	Mary (wife)	1. Jean 2. Sister 3. Son	
<b>Week8</b>	1. Patrick 2. Ruth (wife)		1. Karl	Mary (wife)	1. Jean 2. Daughter-in-law	

The participant profiles presented in the following sections serve as an introduction to the context of each participant's family, social and support network. They highlight key relationships to people, milestone events and memories, described through the interview process and participant discourses. These profiles are an attempt to map some of the complexities and messiness of the situated personal context as described by Clarke.<sup>362</sup>

#### 4.3.1 Patrick

**Patrick** was married, 18 years ago, to his second wife Ruth and he describes her as the 'love of his life'. Ruth has had cerebral palsy from birth. They each have 'one good side' and

<sup>362</sup> Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*.

physically support each other as they walk. Their home is a small apartment which they were able to buy through the gift of an inheritance. They have shops and transport close at hand though taxis are the only really practical means of getting around. Shopping is an ongoing challenge for them both; taxi drivers are not always willing to take passengers for short distances and when they do, it can be begrudgingly.

Patrick has a history of two brain tumours which were removed over 20 years ago. This resulted in high level of disability and loss of employment. His first wife left him at that time and he also lost contact with his two young children not long after. Patrick has only two remaining photos of his children from when they were very young. In a moment of despair he threw out all the photos he had including those of his son and daughter. He describes this as a 'low ebb' when he didn't care about the pictures anymore.

The way people experience disability, social stigma and manage and control their lives is unique to the person and their contexts. For Patrick, his context is inextricably linked to that of his wife Ruth who was born with cerebral palsy at a time when these children were sent to 'special schools'. They were educated differently. Her mother died while she was young and her aunt became her guardian with the responsibility for guiding her. When Patrick married Ruth he was also taken in by Ruth's aunty.

For Patrick and Ruth it has been an ongoing journey dealing with their health issues. The brain tumours, subsequent surgery and medications all had ongoing impacts on Patrick's memory and behaviour. Patrick felt that the problems he experienced, with regard to memory and behaviour, had worsened in the last couple of years with the diagnosis of dementia rather than being dramatically changed.

Patrick found out about this research project through a case worker at the dementia care services he attended. Patrick had asked his case worker to pass on his contact details so that I could contact him. Patrick's case worker confirmed that he had a diagnosis of Alzheimer's disease.

During those years of illness and recovery Patrick's dad was his rock and his support. He describes this period as traumatic: his behaviour was erratic and it took a lot of trial and error for the doctors to get his medication right. Patrick spent some time living with his dad but felt he was holding his father back so he moved out and found himself living in boarding houses.

Patrick was the oldest of eight siblings: five boys and three girls and the only one who completed a professional qualification to graduate as a carpenter and joiner. As a result of illness Patrick could no longer pursue his trade and worked in a sheltered workshop for many years. It was Patrick's hobby of woodcarving and the ability to repair old furniture which would give him so much pleasure though he could not bear to sell the restored pieces of furniture.

Arranging to meet up with friends and socialising also has its own obstacles, particularly when as they both explain “your friends are in a similar situation to you”. Housekeeping is a challenge for many reasons. Patrick and Ruth, like their friends, are very self-conscious of how their home is when guests come to visit.

Patrick has always loved sport especially football and cricket which he played in his youth. He admits that he did not have the finesse as a player and is content in being a spectator. They live near their church and speak openly about their involvement in the church community. Patrick’s relationship with the church has at times been a rocky road. Patrick’s wife Ruth was present in all the interviews.

#### **4.3.2 Karl**

Karl lives at home with his wife Mary. Karl was married at the youthful age of 21 and proudly acknowledges that Mary is the best thing that ever happened to him. They both love the garden and are very proud of their family home. They have four children and several grandchildren. Family is incredibly important to both Karl and Mary. Even though he cannot remember all their names at times, their birthdays and events are carefully recorded in his diary and Mary takes responsibility for sending the cards.

Karl worked as an accountant most of his life. His meticulous attention to detail has driven him to contribute to improving systems in his workplaces. His career includes positions in banking, the ‘rag trade’ and a high profile sporting organisation. Sport has been a major preoccupation from an early age. As well as playing sport he has supported the sporting clubs his children attended by performing treasurer duties and managing their accounts.

Karl’s diagnosis of Alzheimer’s disease in his late 70s was traumatic. He remembers it clearly because it was his wife’s birthday. Mary went out and didn’t take the key. He was in the house alone and became unconscious. When Mary got home she called the emergency services all of them arrived: the fire brigade, ambulance and police. He woke up the next day in hospital and further investigations revealed the diagnosis.

Karl and Mary still enjoy golf though playing is getting harder as they have to share the same buggy and hence take turns to play.

Karl’s wife chose not to be present or participate during the course of our interviews. Mary supported the activities by searching out artefacts we could use in our interviews which included things such as photos and news articles. Mary also helped out in the final review of the life book by checking the names, dates and events which Karl sometimes had difficulty remembering or placing.

#### **4.3.3 Jean**

Jean moved to her current home 10 years ago to be closer to where her adult son, daughter and grandchildren live. Her children, their spouses and the grandchildren share in caring for and supporting Jean so that she can live with relative independence in her own home. Jean

adores her family (and the dogs who are considered part of the family) and talks about why each of them is so special to her.

Jean grew up during the Great Depression which occurred during the 1930–40s. Jean remembers what it was like to live in a small home with a supportive extended family. She has an older sister who lives not too far away and comes to stay with her regularly. Their little brother died of meningitis as a small child and his loss impacted heavily on their mother who withdrew emotionally for several years.

At the age of 15 Jean attended a business college and then worked as a secretary in a number of companies prior to getting married. Her husband Tom was very artistic. Together they had a son and a daughter who are both also very creative. Jean lost her husband due to a heart attack when he was in his early 40s. Her parents lived nearby at the time and were a tremendous support. Jean never remarried but since moving she did have a special friend whom she nursed until he died of cancer only a few years after they met.

Jean has a number of long term friendships which she treasures. There are the friends Jean grew up with. There are friends with whom she would go on combined family holidays and day trips. There are also those who supported her when her husband was gone and friends she has supported when their spouses died.

Jean's family were in the Salvation Army when she was young and she continues to participate in a local church community of a different denomination.

Jean was diagnosed in her early 70s with Alzheimer's disease. It was getting lost and losing things which started to cause problems. Her family started taking Jean to the Memory Lane Cafes run by the local Alzheimer's association and it is here that she sometimes catches up with an old friend who just happens to attend at the same time.

Jean's interviews were generally accompanied by at least one member of her family and sometimes more. It was only on a couple of occasions where it was just the two of us while the family members were present in another part of the home.

Taking due care to get to know and understand participants as real people in the contexts of their lives is a central and significant component of undertaking this type of archival work. Knowing their stories of life was the foundation and anchor for how we could co-create records that were person-centred and had sustained meaning for the participants.

#### **4.4    *Getting to know the participants: Interviews weeks 1–2***

Integral to undertaking interviews with each participant was the need to understand their voices, contexts and their perspectives as well as records. The interviews with each participant were conducted over several weeks. As explained in Chapter 3, a range of processes and practices were implemented to explore working with participants and studying records. The constant comparative method, as a systematic and iterative approach, encouraged cumulatively

investigating findings as they arose. It also supported progressively implementing a repertoire of techniques appropriate for working with people to collaboratively explore their voices and perspectives. The rest of this chapter describes the findings in relation to the innovations that were effective while working with people to co-create person-centred records. In Section 4.4 I address the significant activity of getting to know the participants and their contexts, particularly in the early weeks of the research (weeks 1–2). These are discussed using the following headings:

- Working with people: Sharing stories, hearing voice and perspective
- Working with data: Thematic analysis – stories as perspectives
- Working with people and data: Mapping the personal and broader contexts.

#### **4.4.1 Working with people: Sharing stories, hearing voice and perspectives**

First impressions count. I began the first interview with generic questions, devised in the research design, to begin the conversations and gather important demographic data. But I was quickly surprised by each person's openness to disclosing life events which were sometimes very sensitive. It was like throwing a pebble into the water. Every time a story was told the ripples increased and converged. Like music, it was the merging of voices, which brought to life their unique qualities and the complexity.

The first interviews with each participant were fundamental in establishing rapport and open conversation. The storytelling events were oral records. As oral records they were shared between people. The stories were meaningful but there were many stories and their boundaries were soft. Sense making was in itself a process of making meaning. Our conversations blurred and echoed in my memory. Details of those conversations faded in my memory but they did not disappear. On the contrary, they were transformed through the evolving relationships. I was developing knowledge of each person's world. We shared and reviewed stories. It was those stories which affected me most powerfully that stayed with me. These conversations became my memory of another's life events and states of being. They also became part of my own stories as shared memories.

These same storytelling events were contemporaneously audio-recorded and then transcribed. I used photography and drawings to record images of objects we discussed or sometimes people as they engaged with those things of meaning. I decided in that first interview to not take notes. My attention and focus in these conversation had to be on the person. I could not look a person in the eye and at the same time write notes about them. I needed to observe their face, listen to their voice, learn their mannerisms and feel their responses. Many times I would sit in the car at the end of an interview and record those meaningful impressions while they were animated. I reflected on our interactions and activities directly after leaving participants and wrote these notes as memos (as described in Chapter 3).

#### **4.4.2 Working with data: Thematic analysis – stories as perspectives**

The initial stages of analysing data involved conducting thematic analysis, open coding incidents and in vivo coding of the interviews and the transcripts. This enabled me to explore

and begin to identify what was meaningful to each of the participants in their personal setting. These themes, codes and categories are italicised, as they are discussed in thesis.

Thematic analysis was a process of observing, sensing to understand, coding and then interpreting the data and its meaning. I began with line-by-line analysis of the open interviews; which revealed what Boyatzis describes as “life stories...or autobiographical data. Telling stories about one’s past experiences and events is a method of communicating *emotions*, transmitting *cultural values*, and *creating a history*.”<sup>363</sup> There were stories illustrative of important moments for each participant.<sup>364</sup> In these personal stories participants were speaking about: significant *people, objects, events*, and *relationships*. Participants were also sharing their own insights into why these topics of conversation were meaningful. Their stories reflected:

- Who the person was; their identity
- Relevance to the person in how they represented self
- Relevance to the research in exploring the concept of the personal record
- Insight into understanding the person and their contexts: past, present and future
- Stories which had some emotional impact on the person.

Thematic analysis revealed that participant stories were narratives within narratives. Thematic analysis of the data provided sensitive and reflexive approaches to teasing out the personal stories; these were the codable moments which I describe as the *milestone memories*. This process of disentangling one story from another was a way of both simplifying the content for review and also realising the underlying complexity of *personal stories*.

I was working with people in their situated context, in a nuanced style, using my own insights. These were my interpretations from a single interview. As part of this constant comparative analysis and reflexive practice I then sought to extend my understanding of how participants perceived their broader context.

#### 4.4.3 Working with people and data: Mapping the personal and broader contexts

The people I interviewed were telling me stories about people who were part of their situated contexts which extended beyond the family or home. I discovered in the first interview with participants that their perceptions of personal context were difficult to describe, yet alone articulate in detail, and hence even more difficult for me to interpret. In response I implemented personal mapping with each of the participants in the second week of their interviews. It was a technique for making explicit what I was hearing and how I was interpreting participant perceptions regarding their situated context.

Using butcher’s paper and markers I initiated conversations regarding who or what the participant identified as being part of their social or support networks. I created two separate

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<sup>363</sup> Boyatzis, *Transforming Qualitative Information: Thematic Analysis and Code Development*, 67.

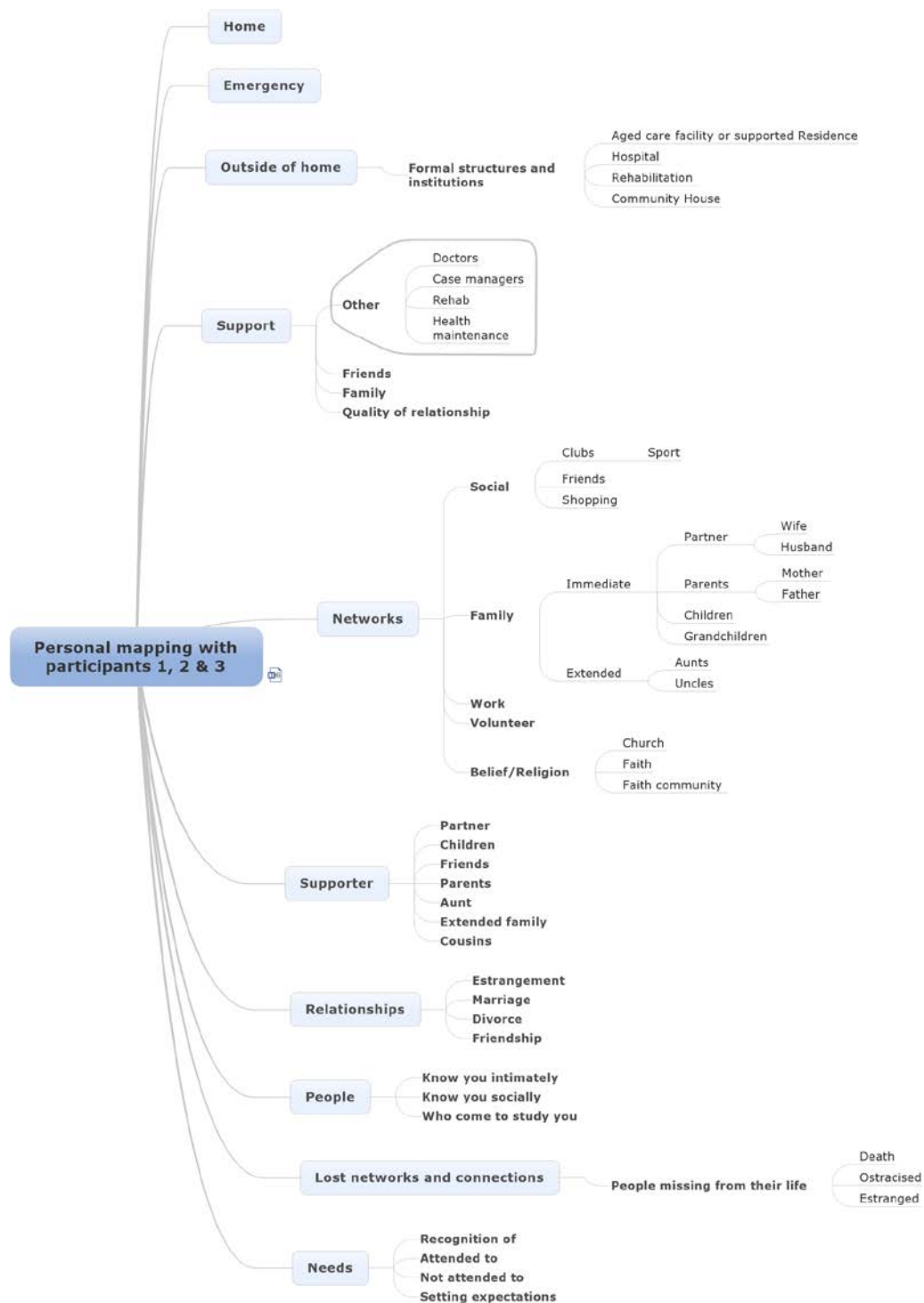
<sup>364</sup> *Ibid.*, 1.



maps with each participant; one map for the social network and another for the support network. As the participant spoke I wrote and drew on the map. These maps were brainstormed and as such incorporated a range of elements discussed. The maps also served the purpose of making explicit and tangible what I had heard and understood. I wrote down names and lines of relationship between people and places. The participants and I were able to point to elements on the map in order to clarify who or what we were talking about.

The personal mapping was an orientation into the participants' worlds and their perspectives of where they were positioned in relationship to other people. This information was important in creating participant profiles. In conversation the participants did not distinguish great differences between their social and support networks. I found that the social network consisted of people within family, friends and informal associations. Support networks included family, friends, health carers and institutions. The two networks overlapped significantly. Family members were an important part of the support network and support within institutions such as church or sporting groups included friends.

Further analysis of the mapping outcomes revealed some salient insights into how the participants considered who or what were part of their networks. This analysis is illustrated in the comprehensive map (Figure 15).



**Figure 15** The map format used to summarise key information about each participant

The mapping provided interesting insights into the worlds of participants. Some of the people who I thought may have been included in their social and support networks either did not appear or were not prominent. An example of this different perception was the position of the doctor or health care professional in the map. I had to ask the participants explicitly if they would consider the doctor or other health care professional as being part of their support

network. I understood that the health care professional, such as a doctor, was not a close connection. Participants seemed to make decisions regarding who was included in their support network based on the *quality of the relationship* they had with the person or institution, rather than the role they played.

It also became evident that social and support networks were built on mutual connections shared with family or spouse. An example of this is that when Patrick talked about people who were in his support network, he also included people in Ruth's support network who supported them both. I did not create an individual map for the spouse or carers involved in the participant interviews. It was the mapping process which allowed me to visualise connections and relationships. We revised the mapped networks in light of the discussions to include other family and friends who Patrick could possibly call on if he needed help. Mapping was an exercise in trying to further understand personal contexts, perspectives, and relationships; their inherent meaning with regard to decision-making and how personal records might be used beyond their immediate context.

I tried to explain to the participants how this exploration of personal stakeholders was preparatory work and that we could use these understandings of relationships to explore how stories, and their representation through the records we created, might be shared. I realised how difficult it was to understand the concept of the *personal record* or how these records might be shared if the participants and I did not have a shared understanding of what those personal records were. This experience highlighted for me that the archival language can be abstract. A term such as personal records needed to be both explored and translated in a language that was relevant to each of the participants.

These findings, of how participants perceived their situated context, have implications with regard to recordkeeping. The findings raise the importance of not only identifying who possible stakeholders are but also the need to understand how they fit into an individual's personal schema. Interpersonal relationships do influence the decisions participants make regarding what can be shared. In terms of archival theory and practice, these results reveal techniques that were effective in the context of people with early dementia. Significantly these included ways of listening to stories, hearing voice and understanding perspectives; working with data thematically to signify the participants' perspectives; and creating understanding of people and their broader contexts in order to situate people and their data.

## **4.5 Findings: Developing Knowledge in Situated Contexts**

Personal mapping of the broader social context helped identify and learn more about significant people and networks in the lives of participants, many of whom were represented in their personal stories. The exercise also raised further questions regarding the relationships participants had with those meaningful associations, and in practice the stories I was analysing.

The social constructionist lens in this research highlights that “knowledge is contextual” and created within shifting social contexts.<sup>365</sup> Developing new knowledge demanded paying attention to the contexts within which people lived. This section focuses on the findings in relation to situated contexts as a fundamental to understanding how participants perceived themselves within these changing contexts. There are eight sub-sections which address the following aspects:

- Seeing the world through the eyes of others
- The impact of dementia is like the walls closing in
- Making time and place for sharing stories and records of meaning
- Stories are the way we construct identity and sense of self
- Actively remembering from the present: Remembering and forgetting is a continuum
- Tools for remembering
- Personal stories to vignettes.

#### 4.5.1 Seeing the world through the eyes of others

All three participants expressed through their stories and *feelings* that others had made assumptions and sometimes decisions about them based on perceptions of how dementia affects a person. Patrick explained how he was very conscious of his episodes of aggression. Even though he had no control over this behaviour he felt that others would not understand. Jean explained on a couple of occasions that the doctor and family had decided she should not be driving anymore. The loss of mobility had impacted on her independence in visiting friends and even doing shopping. In 2012 Karl undertook his routine driver's licence exam and failed. He believed that he had been judged unfairly because the examiner was aware of his diagnosis of Alzheimer's disease. He took it upon himself to find another driving examiner. He redid the test and on this occasion passed.

In this quote below Karl is reflecting on the retaking of his driving test where he felt unfairly judged by the driving instructor because of the diagnosis of dementia. He wanted his driving to be evaluated on the basis of his practical skills not as the person with dementia.

*Karl: Well, they say the Alzheimer's, but I don't have any trouble knowing the traffic, knowing where I am and all that jazz, so I think they're up the wrong tree with me. So that's probably one of the problems, they think they've gone through all this theory business, but they're not practical. And it's just their opinion, that's why I'll see with these others, another completely different mob say, and they won't know who I am.*

The effect of Alzheimer's is different for each person. Participants also expressed gratitude for those people closest to them who supported them as the need arose. They sometimes spoke of the cognitive changes they experienced and the impact of this on the lives of those around them particularly at home or in those places of connecting with others.

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<sup>365</sup> A. M. Koch, *Knowledge and Social Construction* (Lanham, MD: Lexington Books, 2005), 17.

In light of these life changes being experienced by each participant, there were some strong themes which arose through our conversations. These themes reflected personal concerns in sharing their stories.

- Patrick had expressed concerns regarding the way that his behaviour might be interpreted by significant people in his life. He could see how the memory loss had affected not only him but those who loved and cared for him. We discussed the possibility that his vignettes might serve as a tool for expressing what was happening for him.
- Karl explained that the family had heard all his stories before and that they might not be interested in the records we were creating. His enthusiasm for sharing his stories of self to me as a listener was overwhelming. Karl highlighted that I needed to understand how accountants think if I wanted to understand him. Accounting was more than a profession. Karl paid attention to the details and the rationale for actions.
- Jean was a very social person. A key theme in Jean's stories was the significance of each family member and her friends, particularly how they would help each other when times were difficult or loved ones lost.

#### **4.5.2 The impact of dementia is like the walls closing in**

When first entering into a participant's homes and engaging in conversations, it was easy to make the assumption that a person's home is in itself a complex and integrated record of self. The homes of participants were furnished with belongings; functional, of particular meaning, unique to the individual or shared. Due to cognitive changes associated with dementia, the relationships were changing between the person with dementia and their family, and even with the environment they lived in. I describe this effect like the walls closing in. Participants were increasingly depending on family to facilitate activities. This facilitation of activities extended to the management of personal records and belongings in the home.

Even though Karl had a lot of memorabilia, it was his wife Mary who, for the interviews, would bring out from storage meaningful objects; select boxes of photographs, club magazines, newspaper cuttings, or other materials which might be useful for our discussion. Karl would browse the items and focus on what caught his attention. And then the stories would come. The stories were not just about the objects present. The telling of stories in relation to objects and other stories was recursive. The stories were reiterated in relation to other stories, people and events, and me.

The way each of the participants engaged with their personal records was quite different. The concept of personal records was complex and incredibly nuanced. In practice, understanding personal records became much more about understanding the social context each participant lived in and what was meaningful. Along with his photos, memorabilia and personal relationships, Karl's diary, the fish pond and even the cat all had special significance. The affective nature of these was powerful and evidenced in how Karl engaged with objects and animals as well as people. Older personal belongings that Karl had collected in his lifetime were stored away. It was his wife Mary who would bring those things of meaning out for our interviews. Even though Karl's conversations were often memories or reflections of the past,

the environment he lived in was his present and the point from which he engaged with me and others.

Jean was content sitting and talking at the kitchen table even though her home was filled with objects, photos and artwork created by her and her family. On occasions I would ask her if she would like to show me some of the objects she had spoken about in our conversations. What struck me most was the change in Jean's demeanour when she spoke about the meaning of her records. The meaning was something Jean experienced and made explicit as she shared her stories. It was an *emotional experience*.

As was the case with Karl, some of Jean's personal effects were not always at hand. For obvious reasons some belongings were stored away. The wedding dress was hung up in the wardrobe. The old china dolls were broken and delicate so they were in a 'safe place'. There were meaningful objects and photos which were in the possession of other family members and Jean questioned why this was so when she realised that this was the case.

The image in Figure 16 is of Jean taking her wedding dress out of the wardrobe. She obviously enjoyed looking at the dress and took pleasure in recounting the stories of how it was made and who had worn it. (The picture has been modified for the thesis to preserve her identity)



**Figure 16 Jean reminiscing with her wedding dress**

Patrick expressed a great sense of loss over all the photographs he had disposed of after his divorce many years prior. This sense of loss reminded him of estranged relationships. He obviously treasured the two remaining images of his son and daughter from when they were still very young, though one of these had been put away for safekeeping as it had a broken frame.

I was able to take this co-constructed knowledge of the person back into the interview context and ask questions with sensitivity regarding those moments that I felt required elucidating. I was making decisions in the research process that were critical to how the study was being conducted. I was considering how records were *social objects*, shared with or sometimes facilitated by others. These were shared activities.

Even though an object might trigger a sequence of stories, what fascinated me was the nature of those stories. The stories were more than annotations of objects and records which existed currently or sometime in the past. These stories being told had not been recorded or documented. Material objects were *traces* to another time and place but they were not the memory. The remembering was an *embodied experience* through which the participant would revisit the event from their *present* with all the *insight* and *knowledge* they had accumulated since that moment in time. They were recalling something from the past but experiencing it anew in the present.

#### 4.5.3 Making time and place for sharing stories and records of meaning

When I met with each of the three participants, we would congregate in the ‘heart of the home’. For Jean, Karl and Patrick this place was at their dining table. It was like the rest of the home revolved around this space. Meaning was very subjective and contextual. Jean admitted many times that she was sentimental and a keeper of things. Her home was filled with objects of meaning. Jean spoke of the things that were around, such as paintings, within the stories she shared. She would show me the objects and their meaning. I felt very much like the object’s existence was in itself a story untold and not recorded. The stories were told in relation to another person, be it myself, family or friend.

Understanding what were meaningful records in the home was not always obvious. If personal records were on display or their retrieval was facilitated by someone then they became *present*. This activity of evaluating what was meaningful required time and thought. At the end of my first meeting with Patrick I left a packet of post-it-notes with Patrick and asked him to stick them on those objects around the house which were important to him. When I arrived the following week Patrick exclaimed “I did all me homework.” ‘Post-it-notes’ were positioned on things in the living room. Patrick explained “Cause these are the memories that I cherish.”

The first and most obvious object, with a post-it-note on it, was a picture frame with the image of a young boy. The picture frame was sitting alone on top of the television. Patrick and Ruth explained that this picture is one of a pair of picture frames which hold the only two remaining photos that Patrick has of his children. Patrick had not seen his now adult children since they were young. He did not know if they are married or if he has grandchildren.

*Ruth: They’re Patrick’s kids [referring to the photo of his son sitting on top of the television]*<sup>366</sup>

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<sup>366</sup> Patrick has two children from his previous marriage and he had not seen either of his children since not long after the divorce. Both children would be their 30s now. He only has one photo of each child.

Joanne: Oh...so who is this?

Patrick: My son, my son

Joanne: And how old is he?

Patrick: That was taken many, many years ago. I haven't seen him since.

Joanne: So what about your daughter? Do you have a photo of her?

Patrick: I do...

Ruth: Yes that's her

Patrick: No, no no no no...it's broken Ruthy, the frame remember...I broke the frame. I put it away somewhere so it wouldn't get lost.

Ruth: Away, and now we can't find it.



**Figure 17 Vignette (Patrick's children)**

There were stories behind and within the stories. These photos were part of a bigger collection. Patrick had made decisions based on how he felt regarding his life, context and family at the time that he had disposed of the other images. These photos of Patrick's children were the only images he retained. We were exploring not only what remained but the *absence* of other records which represented to some degree the story of Patrick's past. These records were gone and that *absence* represented the *estrangement of family*, and in particular, his children.

It is Patrick's personal collection of these records which were gone. There may have been originals or copies in other contexts but they were not available to him. Patrick had the memory of how and why he disposed of these personal records. In some way the disposal of these records reflected agency; Patrick did not want to be reminded of them at that time. Patrick was *affected* by these *records of self* and family. They were a disturbing reminder of *fractured relationships* and *lost control*.



The telling of the story was a type of personal recordkeeping. The stories as told were explored through conversations, the analysis of audio-recordings and transcripts. They revealed the personal records which were what I would describe as '*missing in action*'. Sometimes there were traces. There may have been a photo or an object to which the story related. Other times not. We may not have been able to bring those records back, or, change the chain of events. We could create new records which attested to those stories of life which are an integral part of who we are. The participants and I could co-create records which centred on the perspective of the person in their ongoing present. We could co-create new records of what was absent or lost to the current context.

#### 4.5.4 Stories are the way we construct identity and sense of self

Listening to these stories and studying their meaning with participants highlighted the delicate relationship between the person and their stories as personal records. As Gergen explains, telling stories is integral to how we as humans construct our identity and sense of self. This process is iterative and ongoing. Gergen emphasises the need to know the stories in relationship to the person. It is only through maintaining this connection that we can understand the implications for action.

For the constructionist it is important to listen *twice*, once to the content of what people say, but second, to what this content implies for the actions that follow. To appreciate what is at stake here, consider the sense of identity...our sense of identity is vulnerable and subject to change...one's self definition is largely created within conversation...one does bring into relationships a sense of self – sometimes quite persistent. However, this firm sense of self owes its existence largely to preceding relationships. And the durability of the past is always in question. The self is always a work in progress.<sup>367</sup>

As archivist and researcher studying personal records, Gergen's words were a salient reminder that we are the stories we tell. I took on the challenge to develop techniques for studying the stories of memory and identity, as described by Gergen, and as a 'work in progress'. As the researcher this meant identifying the stories, shared in the interviews, and studying their content to determine how they reflect the person's sense of identity; as something dynamic, a social construct, experienced through conversations and relationships.

One of the key challenges confronted in applying a social constructionist lens to applied archival research was the teasing out of the stories. The stories in this research were many. They also became *my* stories as researcher and of the research. They were the unique and *personal* stories of three people with dementia who participated in this research. They became *our* stories as we brought to life a present which was co-constructed through creating records with personal meaning. The process of co-creating records was part of the storytelling and inextricably connected with the content of the stories, their contexts, meaning and action. These were inseparable. Gergen explains how

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<sup>367</sup> Gergen, *An Invitation to Social Construction*, 2009, 69.

empirical findings can generate vivid illustrations of perspective: While not themselves proving (or disproving) a theory...They can inject life into an idea in a way that helps us to appreciate its significance and plausibility. In this sense good research in the social sciences can function like photographs in journalism or eye-witness accounts on television. We are moved and absorbed...empirical results can speak with a powerful voice; we can literally visualise the issues in “real-life” terms...empirical methods can provide useful information and generate predictions of broad social utility. The empiricist tradition offers much, but is simultaneously limited. For participants in the constructionist dialogues, these limitations have served as invitations to innovate.<sup>368</sup>

In the context of creating such rich and complex data, I was as grounded theorist and personal record archivist listening to participants and discerning their stories for voices as “vivid illustration of perspective”.<sup>369</sup> Transpiring through the conversations and stories were discoveries of signs, patterns and discord which would help me to know and understand the person I was interviewing and exploring the concepts of records with personal meaning.

#### 4.5.4.1 We live life in routine - think once – the content

As archivist and researcher it was important to understand the content in the participants’ stories and what the meant for them as people. “Think once”<sup>370</sup> – content was an important way of attending to this in the research. In the following paragraphs I share an example of content theme *we live life in routine*.

The significance of the stories varied; they were situated and perspectival. It was one of the first interviews I conducted with Patrick. I was surprised to hear Patrick’s wife Ruth note how in these conversations she was hearing some things for the first time about Patrick’s life and his personal experiences. Ruth’s words drew my attention to how the research process created new contexts which differed from the day to day routine.

*Ruth: ...there’s a lot of things that I don’t know about Patrick and it’s coming out now, [in these interviews] so we’ve been together for a long, long, time now, and you know how a married couple just live day-to-day they don’t delve into the past. [my edit]*

There were many moments such as this, some more obvious than others, where I was conscious as to just how much I was learning from participants throughout the research. The significance of these moments is not solely about the research topic. They were insightful observations about life which influenced my own perceptions and illuminated key concepts within the research. It was this of type reflexive practice which provoked me as a second generation grounded theorist to interrogate my own experiences in relationship to the experiences of research participants.

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<sup>368</sup> Ibid., 62.

<sup>369</sup> Ibid.

<sup>370</sup> Ibid., 69.

Through the private lives of others and the context of research, I had to learn how to navigate multiplicity of stories, perspectives and concepts of personal recordkeeping. Rendering complexity without diminishing multiplicity is a key challenge of postmodern influences shared across records continuum theory, social constructionism and theories of personhood.

#### 4.5.4.2 Think twice – implications for action

Similarly, reflecting on the implications of this content as researcher and archivist, ‘think twice’ was a useful mechanism. The mantra was ‘think twice – what are the implications for action’.<sup>371</sup> The research process is disruptive. Through the research interviews we were making time set apart from the routines of daily living and in some ways the relationships of every day. I was a *third party*. Over the several weeks the participants and I met together to converse, share stories and review the vignettes we were creating a new ritual and a special space dedicated to them, their stories. We had the luxury of time with undivided attention.

With each participant I entered into a new context with unknowns that would need to be explored progressively. Alzheimer’s disease is diagnosed in relation to specific types of cognitive and behavioural changes a person experiences. The phenomena are not the same for each person; they are unique in their presentation. I needed to work within the unique set of skills, ability, and capacity of the person in relation to communication, records and technology. The processes, methods and techniques being implemented in the course of the interviews would need to serve the goals of research and support specific needs of each participant.

**Table 10 Categories of meaning: Ritual of meeting and conversation**

Ritual of meeting and conversation
<ul style="list-style-type: none"> <li>• Open interviews</li> <li>• Conversations</li> <li>• Situated in the person’s home</li> <li>• Friendship</li> <li>• Trust</li> <li>• Caring</li> <li>• Listening</li> <li>• Nurturing</li> <li>• Respect</li> <li>• Using vignettes to reflect back what is heard in conversation</li> </ul>

The researcher and participant relationships constructed in this research, though located in defined time and space, had affect beyond the physical encounter (see Table 10). Wilson describes research as ceremony. As an indigenous researcher he explains how relationships *are*

<sup>371</sup> Ibid.

reality and “space between people and the environment being sacred”.<sup>372</sup> Wilson explored the importance of ceremony and relationships with indigenous elders, not only within society, but also in the context of research. He puts forward some key concepts and their relationships in developing a worldview, which he explains is compatible with both indigenous and non-indigenous communities:<sup>373</sup>

- The spiritual part of research is ceremony and is when all the connections are made.
- Spirituality is “integral to health living for all people” along with “mental, emotional and physical health”.
- “Relationships do not merely shape reality, they *are* reality”.<sup>374</sup>

It is this sense of the relationships as sacred that the spiritual became for me a salient lens through which to explore what is sometimes intangible; the bridge between internal and external self. Spirituality was not simply about giving name to religion. The spiritual was another kind of knowing through which beliefs and values could be explicated and manifested in ways that surprised me.

I was being observed as much as I was observing. I found out early in my interviews with Karl that he ‘rates’ people that he meets – out of ten. It took all of the weeks of conversations for him to finally admit that I ‘passed’ and then he did it with a smile on his face. Patrick and Ruth explained how they felt like I had become a friend. Family members took time to catch up with me particularly at the beginning of each interview session. They sometimes sat with the participant and me as we spoke or would be able to hear us speaking from another part of the house. Each encounter was distinctive. When I entered the house we began socialising which generally included making a cup of tea and small talk was a time for me to “check the temperature” and get a sense of how they were before we jumped into the research activities. This social talk included the carers who were in the home as well as the participant. All the relationships required negotiation.

#### 4.5.4.3 The actions

Based on attending to the content of the stories and the implications for action, my actions were outcomes of this reflexive process which considered not only what I did but how and why. It is the little things that count. I could not overestimate the importance of a personalised approach to working with participants. Each person is unique. I needed to learn about the person, their preferences and routines. Knowing and working in with their personal needs meant arranging to ‘see the person at their best’. Scheduling the right time to meet was important for the participants and depended on several factors. Are they a morning or evening person? Patrick and Ruth are definitely not morning people and I learned early on not to call them before early to mid-afternoon. They stay up late and get up late. Jean and I

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<sup>372</sup> In a personal communication with Wilson he explained that though his research was situated in an indigenous context, it was not uncommon for non-indigenous researchers to be drawing on indigenous research knowledge which focuses on the person and their experience as a whole. S. Wilson, *Research Is Ceremony: Indigenous Research Methods* (Black Point, NS: Fernwood, 2009).

<sup>373</sup> Ibid., 7.

<sup>374</sup> Ibid., 89.

would mostly meet mid to late morning though timing also depended on when a family member could be present. Karl's schedule revolved around his other engagements such as golf etc. I would fit in with their commitments and whether they felt up to meeting or not.

Routine is a way of maintaining memory. Even though we were creating new routines my intention was to not disrupt the pattern of each person's day. I observed how routines for each of the participants were helpful mechanisms for adapting and coping with life. I was guided by the needs of the participant and the carer present in the home. Jean would answer the door on my arrival and was often flustered. The attending carer (one of her immediate family) would arrive not long before me. We allowed time for Jean to insert her hearing aids and attend to other needs such as medications. We would make a cup of tea, sit at the same table in the same place as the week before and simply catch up. We needed to attend to the physical, psychological and social needs as well as the objectives of the research.

In drawing this section to a close, I reflect on how much I appreciate Gergen's advice to think reflexively regarding stories of self and identity. His advice challenged me to think beyond first impressions; to reconsider my actions in relation to what I was hearing and learning from participants and how we co-created person-centred records. In the next three sub-sections I continue to share examples of the techniques that we used for developing knowledge in these situated contexts of the participants.

#### **4.5.5 Actively remembering from the present: Remembering and forgetting is a continuum**

Alzheimer's disease is so often associated with problems of forgetting, yet, I was observing participants learning and remembering. We evolved new routines and rituals. Even though the stories people told may have been recounted from the past they were bound to relationships in the present.

In the context of our conversations Jean did not often speak about her experience of Alzheimer's disease. Jean did however explain how she actively tried not to think about the Alzheimer's disease but is reminded by her own actions. There was a sense of Alzheimer's lurking in the background and she checked on herself with regard to how it manifested. Jean compared where she was at with what happened for her mother who also had Alzheimer's disease. Jean understands the pain the disease causes others when they no longer seem to be recognised by the person suffering from the disease. She knows this has not happened for her as yet. So far she has not forgotten any of her family or friends. I intuited her sense of isolation and even some of the influencing factors such as transport and particularly the loss of loved ones over the years. There were themes in our conversations which highlighted patterns in thinking; not as distinct, but like a tapestry where a single coloured thread weaves its way through a range of visual or textural components of the storytelling fabric.

Karl was the youngest in his family by many years and saw both his parents suffer with Alzheimer's disease. Karl's comments regarding the experience and impact of Alzheimer's disease were thoughtful and would often be said as if *in passing*.

*Karl: I think it's just a gradual loss of memory control, I did see it happen with both my mother and father, I mean it didn't have, they died in the late [19]70s, so that's a long time ago now, and see they were 44 and 40 when I was born, so by the time I came along and I was a teenager, and then we got married, and all that jazz...*

This was not the first experience of Alzheimer's disease for Karl and Jean. They both compared their experiences of Alzheimer's, not only as someone who is diagnosed, but as family and carer of a parent with the same diagnosis. Patrick was very conscious of the changes in behaviour he was experiencing and the impact on others close to him. The Alzheimer's disease seemed to remind him of the brain tumours he had had removed many years prior and their effects. It was confronting. The experience of Alzheimer's disease impacted on the way these people saw themselves as well as how they were perceived by others.

Each participant's life and stories are part of a continuum and in our conversations they spoke from the present. They would retrieve their memories not as past records but rather new constructions in time and place; made up of all those moments that went before. I wanted to understand their individual presence; his or her experience in the present. Aware of the common perceptions the people with Alzheimer's being that they 'forget' I wanted to understand the experience of life from the perspectives of Patrick, Karl and Jean.

#### 4.5.6 Tools for remembering

Karl's diary was one of the tools he used to record and remind himself of those people close to him as well as special events. It was also a way of understanding some of the contexts in which simple recording techniques could help Karl *cope* or, what I might describe as *recover*, when he does experience the loss of memory associated with Alzheimer's disease.

I learned very early with Karl that he struggled to remember names. Karl would speak about his children often. He would tell me the stories but many times the names were absent. He had not forgotten the people. He had difficulty *recalling* their names. Karl's diary was important but it was not up-to-date. Because entries were according to date rather than by name the relationships were loosely connected. As an analyst I was trying to understand the context and the possible requirements. What were their needs both obvious and unperceived? As the information expert I could see how certain information needs could be addressed. When reviewing the personal maps or reviewing the vignettes, I noticed that simply seeing the name of a person or place would allow Karl to recover when a name was absent. Alzheimer's disease can impact on memory and disrupt associations between words and difficulty with recall. Seeing words is described as helping the person recognise and recall what they would like to say.<sup>375</sup>

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<sup>375</sup> J. C. Hughes, *How We Think About Dementia: Personhood, Rights, Ethics, the Arts and What They Mean for Care* (London: Jessica Kingsley Publishers, 2014), <https://books.google.com.au/books?id=pSsEBAAQBAJ&pg=PA60&lpg=PA60&dq=steven+sabat+alzheimer%27s+disease+words&source=bl&ots=xAS1wRKMxd&sig=B2hq0THX67Mv-riYyF0yRQSaif4&hl=en&sa=X&ved=0ahUKEwihvu3f1cbLAhXIN6YKHXMZDo8Q6AEITzAJ#v=onepage&q=steven%20sabat%20alzheimer%27s%20disease%20words&f=false>.

*Joanne: So when you talk about a diary do you mean for appointments and things like that.*

*Karl: Mmm it's a black diary. Yeah, it's got everything in it. It's got all the family you put on the thing [referring to the butcher's paper map] Everybody's birthday on there. Um maybe not the last one cause I haven't got the info on him yet. Ah but all those kind of things I keep so when you open it up I always look at a week and...oh, it's so and so's birthday or we're going away.*

*Joanne: So what do you do when it's somebody's birthday. Do you buy a card?*

*Karl: no, Mary's always bought the cards. No, I never do that, I never have, so it's not that I wouldn't.*

*Joanne: It's ok, I do it for us. I think the women tend to do that sort of thing.*

*Karl: Yeah, no, no I don't. I don't do that. We've had three or four birthdays for grandsons and great grandsons in the last week.*

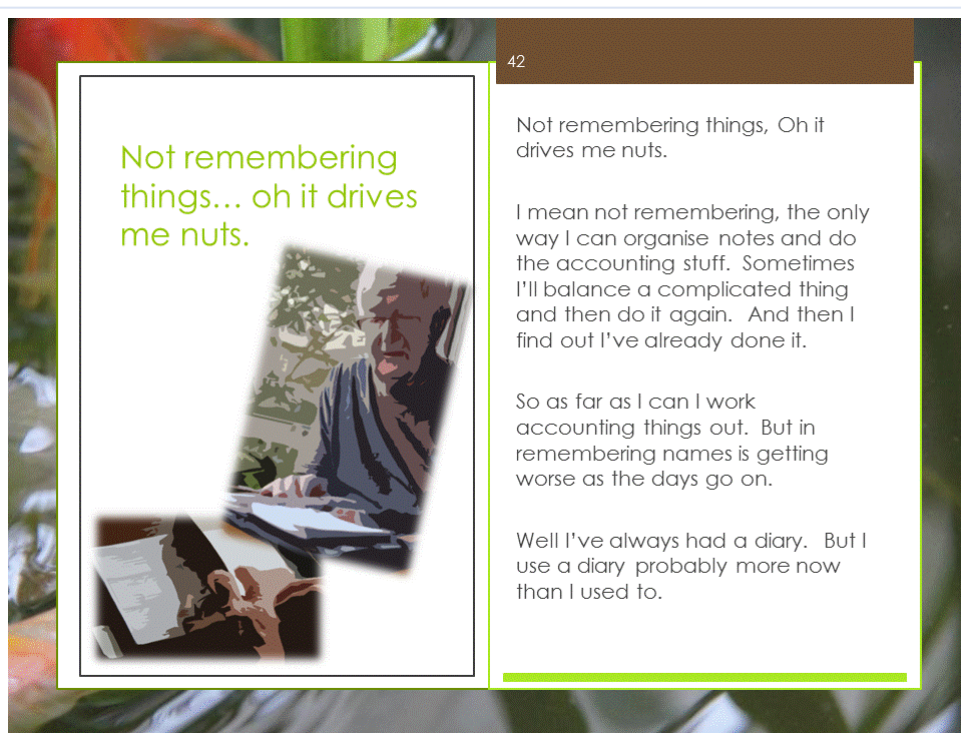
*Joanne: Yeah, so it gets busy.*

*Karl: Yeah. When the mob's like that and for some reason it just a few at this time of the year.*

*Joanne: So if you think about that idea of your diary and the things you want to remember. Do you feel there are other things you want to remember in that diary sometimes.*

*Karl: Probably names. It's the names that have become the major problem. It's not remembering the names. [Karl turns to his wife and asks jokingly] What's your name?*

*Joanne: He's pushing it. [we all laugh] Pushing the boundaries there.*



**Figure 18 Vignette (Karl)**

Karl was keen to show me the diary. We would always sit at the dining table in their open plan kitchen-lounge area. The table was next the window that overlooked a fish pond. Karl was very fond of the fish and especially fond of Nick the cat. (See Figure 19 below)



**Figure 19 Karl with his cat**

#### **4.5.7 Ways of knowing: Exploring voices, stories and personal records**

With each participant I entered into a new context with unknowns that would need to be explored progressively. Dementia is diagnosed in relation to specific types of cognitive and behavioural changes a person experiences. The experiences are not the same for each person; they are distinctive in their presentation. I needed to work within the person's set of skills, ability, and capacity of the person in relation to communication, records and technology.

I learned much from the participants in this research. Though participant stories were unique, my challenge was to understand the content of the stories in this particular context which is both personal and research. I was exploring layers of meaning to the individual. Through reflexive practice together we were able to explore the significance of the stories. What captured my attention was how in interpreting the personal *truths*, (*personal philosophy or lesson of life*) of others I was also interpreting these truths in relation to myself and into broader contexts. These *truths* were not only for a single individual. These *truths* were sometimes the things that were taken for granted, unsaid, the gaps, the absence, or, what we feared to speak. I would reflect upon these personal truths to realise that they also reflected more universal *truths*; gaps in our knowing which is less consciously considered.

Exploring voices and records as a rich diversity demanded seeing through diverse lenses: personal and disciplinary. The concepts of voice and records are both abstract terms. If a metaphor can illustrate the shared characteristics of two different concepts, then, what could I learn through relating the voice as sound to the record as its notation? I created the following metaphor by methodically comparing the qualities of music as voice to the music as notation. It is an exercise in reflexively deconstructing abstract concepts in order to juxtapose and compare.<sup>376</sup>

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<sup>376</sup> Authors Jaccard and Jacoby describe many useful exercises to support theory building. One of these is to challenge understandings of a concept by asking 'what if' questions. With my academic and professional



Music is an intelligent metaphor for voices as records. Music is as an interpretive language, skill and craft. It can be played to give voice to the sound and inscribed as a language in the form of notation. Musical notation is able to communicate the intent of the score when played but it is not the musical sound itself. It is only part of the musical event. The notation is about the sound and the sound in relationship to other sounds and silence.

The meaning of that note is interpreted when played; it becomes a new event. Each note is a sound wave made up of many vibrations. The fundamental sound is the most noticeable sound but there are other waves with higher frequencies called harmonics which allows the sound to resonate and travel. The amplification of this sound depends on the body of the instrument with which it is played, so, the same note can be played to dramatically different effect. The instrument is the situated context. The sound is influenced by the musician as interpreter in the environment in which it is played. The relationship (situated context) of the instrument being played affects, through vibrations, other objects and the environment as well.

“Pitch is a perceptual property.”<sup>377</sup> It is perception that allows us to hear music, notes in relationship rather than as noise. We can attune to contemporaneous sounds as composition and a story which experienced and understood only through its relationship to the other.

Like pitch, recordkeeping is a system of calibration rather than facts. The memory, the record and its description are vibrations of the event. They are tools which create positions in relation to the event but in doing so another event is created. It is a remembering of that which happened and initiated the recording. Like an echo, each time the event is remembered, it is changed and a new account.

A musical score in how it is written or notated is both a record and a metaphor for records as a documentary form. If I equate musical sounds with the trace or event from which a record is created, then I can also envisage how the record as a documentary form is both the interpretation of the event and in each of its readings a new interpretation. A musical score assumes the musician has the knowledge to understand and skills to translate the notation into not just individual sounds but music. This metaphor reflects the delicate nature of the record as a tool for communication. It requires knowledge of how to read and interpret what is recording.

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background in the performing and media arts, I am constantly drawing on the various paradigms through which I have learned to see the world. The idea of juxtaposing two seemingly different concepts revealed an interesting metaphor and new ways of exploring the meaning of a record. J. Jaccard and J. Jacoby, *Theory Construction and Model-Building Skills: A Practical Guide for Social Scientists* (New York: Guilford Press, 2010). Kindle Edition.

<sup>377</sup> ‘Pitch (music) - Wikipedia, the Free Encyclopedia’. Accessed 21 April 2014.  
[http://en.wikipedia.org/wiki/Pitch\\_\(music\)](http://en.wikipedia.org/wiki/Pitch_(music)).

Voices were the perspectives which existed in relationship to each other. In the context of these interviews with participants, I was looking for those discoveries of signs, patterns and discord which would help me to know and understand voices in light of the person I was interviewing. The data the participants and I were creating was not always about what was being observed or heard, it was often listening to the quiet and allowing things to emerge. It required patience and becoming comfortable with my own silence as well as that of others. We were creating new contexts, shared stories, and meaning.

#### 4.5.8 Personal stories to vignettes

In this final sub-section of 4.5 (which has been about the techniques for developing knowledge in situated contexts) I reveal how I moved from working with personal stories to co-creating vignettes as representations of the participants' lives. Exploring the personal and situated context in the first weeks of participant interviews was a critical activity for me as the researcher. It provided the opportunities to get to know the participants by exploring their contexts, personal stories, and begin to understand what was important to them individually. I found on reviewing the interviews as recorded and transcribed that my asking questions was not always the best way of validating what I had listened to or heard. I needed to go back and check that I had understood the details of the stories with some accuracy. It is important to remember that I was concurrently analysing the collected data and progressively undertaking analysis and coding. (See Chapter 3 Section 4.5.1 Coding in grounded theory) I agree with Urquhart when she argues that "coding is a very subjective process."<sup>378</sup> The process of analysis and coding using constant comparative method is messy. It is an interpretive process in which the researcher constructs new knowledge through the layers of analysis, understanding and learning. Explaining what is eventually learned requires some deconstructing of those acts and outcomes.

The interviews with each participant were transcribed and analysed progressively. Implementing the constant comparative method meant that the newly collected or, as in the case of this research, co-created data were being studied in relationship to the data which had previously been collected and analysed. From the first week of interviews the analysis of data highlighted the crowds of stories and their embodied qualities. I began by coding for personal stories as large chunks of data. This was an iterative process in itself. It required transcribing interviews, listening and often re-listening to audio-recordings. I analysed for what I perceived to be those stories illustrative of perspective as described by Gergen.<sup>379</sup> For each participant I created a separate PowerPoint document and inserted each story into an individual slide.<sup>380</sup>

As I conducted and analysed the interviews, through weeks 1 to 3, I continued to review, refine and add to those personal stories, forming them into vignettes. It was only in week 3 that I began to take the first versions of vignettes to review with participants. It was a

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<sup>378</sup> Urquhart, *Grounded Theory for Qualitative Research: A Practical Guide*, 96.

<sup>379</sup> Gergen, *An Invitation to Social Construction*, 2009.

<sup>380</sup> I often use PowerPoint as digital index cards but with added functionality. I can insert text, images and annotate. It is also easy to move or reorder slides.

conscious decision to delay the review process as I did not want to limit the conversations to those stories recorded.

These findings revealed that personal storytelling was a key activity in understanding how these participants portrayed their own unique contexts and how they positioned themselves in relation to others. This insight was instructive to my archival process. I needed to see the world through their eyes. I understood that the impact of dementia is like the walls closing in. I grasped the importance of making time and place for sharing stories, and that these are records of meaning. I heeded Gergen's advice to think three times by considering the content, the implications for action and the actions themselves.<sup>381</sup> I learned that the vignettes had to represent the participant's constructions of identity and sense of self. And, I learned that these were tools for remembering. As a set of findings, all these processes can become tools and activities to assist the personal archivist who is seeking to develop knowledge in the situated context.

## **4.6 Co-Creating Vignettes as Person-Centred Records: Interviews Weeks 3–8**

Building on the knowledge of the personal and situated contexts of participants, there was a need to work with their stories of self so that we could co-create vignettes as personal records. In this section I discuss the methods and processes used to do this. Four sub-sections are used to achieve this description these are:

- Co-creating and reviewing the vignettes
- Anatomy of the co-created record
- From vignettes to life book
- Vignettes and life books.

### **4.6.1 Co-creating and reviewing the vignettes**

As I conducted the interviews and analysed the data, I could intuit or interpret how personal stories were illustrative of personal incidents, concepts and themes. I also wanted to hear what the participants had to say in light of those stories I had through the coding process *selected* from the many. I wanted to check with participants regarding how effectively listened and understood. Had I transcribed, analysed and interpreted effectively? Were these records of research meaningful in terms of how they represented the sense of identity and self for the participants and did this create quality data for the research? I didn't go into these conversations in the first instance asking to see things. I went in wanting to discover what it was that the person wanted me to see and know. These questions I was asking were about challenging my own assumptions in relation to how I was collecting and interpreting data.

The process of wayfinding as described in Chapter 3 embodies the approach I took to determining the appropriate paths or processes for working with each participant and their

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<sup>381</sup> Gergen, *An Invitation to Social Construction*, 2009, 69.

records. Creating vignettes from participant stories was a technique for analysing the interviews. Reviewing the vignettes, as the outcome of analysis, became a process co-constructing the vignettes.

I had purposely waited to commence the review of vignettes as I did not want our conversations to be focused on only what had been previously told. There was space to allow the engagement and conversations to evolve. It also took time to familiarise myself with the participants and understand what was not recorded in the transcripts. What was absent in the research records was important in making decisions.

I took along printed versions of the vignettes, which I had been creating through thematic analysis and in vivo coding, to the week 3 interviews. In creating the vignettes to this point I was attempting to capture key stories which reflected the personhood, and maintained the participant's voice; their wording in the way they told the stories. I had cut and pasted individual stories from the interview transcripts into individual pages without editing. The participants and I began the review of the vignettes together. It was in reviewing these vignettes that I began to perceive what was not documented on the page but was rather the personal and *embodied experience*.

I began the review of vignettes in week 3 by asking the participants to read the vignettes I had created from their interviews and check each of the stories for accuracy. Patrick had stated in the first interview that he had problems reading so the process was modified. I would show Patrick the vignette (some of which also contained a photograph) and then read the story aloud so that he could comment. Both Karl and Jean were able to read the vignettes and did this voluntarily.

I was trying to determine if the vignettes were a sound representation from the participant's perspective. It was important to explore how or why certain stories were meaningful. How could I learn about a person's embodied experience and the affective nature of the records as they were shared and co-created? In understanding the meaning of these records in the broader social context I also wanted to understand how the participant would be prepared to share each of their stories and with whom.

The interviews with each of the participants, from weeks 3–8, comprised of further exploratory conversations as well the review process. Even though each interview was scheduled for two hours, reviewing vignettes required a great deal of concentration on behalf of the participants. It was tiring work and difficult to sustain. I started each session with the reading and review making sure to allow time to extend the topics of conversations. In practice, the review of a single vignette would commonly lead to the participant sharing other associated stories. The stories were like triggers to other thoughts which were not always obviously related. So, we would talk in circles and then come back to reviewing the vignettes.

Throughout the review process, I would correct the vignettes on paper according to participant comments and observe their use of the record. I learned to limit the quantity of

text on the page and increase its size to improve legibility. Post interview I edited the vignettes in light of these corrections and other conversations.

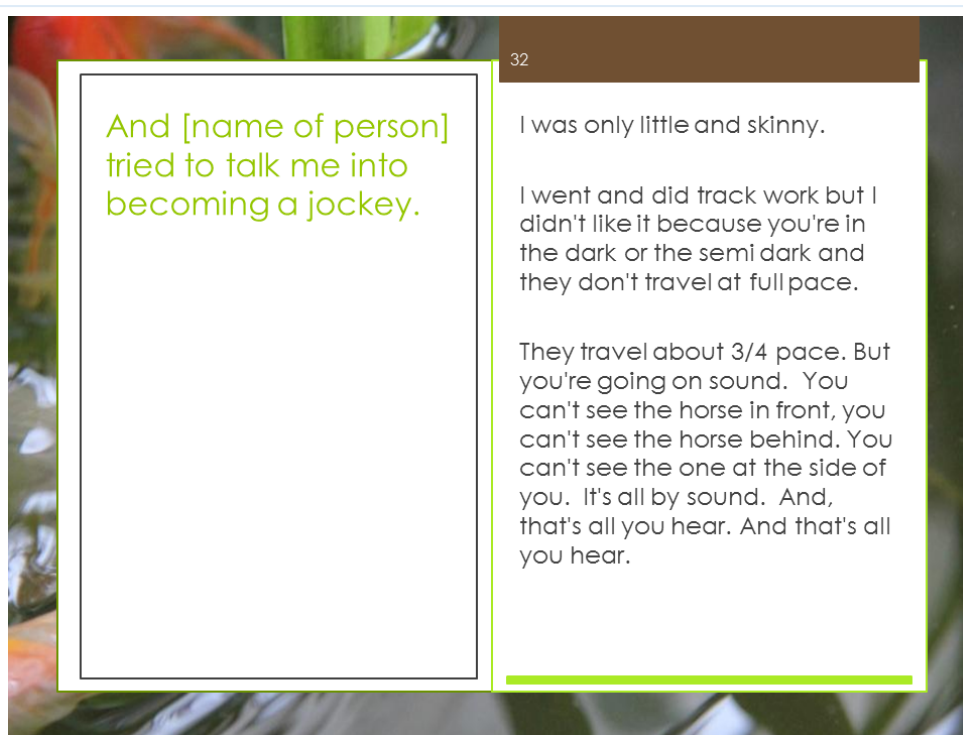
#### 4.6.2 Anatomy of the co-created record

The record co-creating process was made up of iterative cycles of collecting stories as data, co-creating vignettes, reviewing and editing the vignettes as personal records. Where the stories might have been long or tangled with other stories I was able to refine their content by analysing for the core story.

The elements of the vignettes as constructed in the personal records were not only stories but also usable and aesthetic artefacts. For each vignette I also created title or caption in the form of a phrase. Though based in methods for research, the co-creating these records was also a creative act. This was described in the previous chapter. I drew on the knowledge I was developing of each individual in order to:

- Create representations of a person's stories and their voice. By using the transcribed stories and editing only to make the text legible I was able to retain those expressions and ways of speaking that are unique to each individual.
- Check my interpretation of these personal stories, through the review of vignettes' content and the meaning, with the participants.
- Edit the story/vignette in response to participant comments.
- Add stories as vignettes raised in further interviews.
- Personalise the template I used for the creation of the vignettes with a meaningful image.
- Form relationships between personal story and images which gave insight into the experiences of the person, not only from the past, but as they were remembering from the *here* and *now*.
- Through in vivo coding of the stories and vignettes, I created a title/header for each vignette to capture attention of the reader.

Figure 20 is an example of the vignettes I created. There were occasions where the participant did not have an image/photograph associated with their particular story. As was the case with this vignette I was able to find an image on 'free clip art' which complemented the story being represented.



**Figure 20 Creating vignettes (Karl)**

The vignettes were a representation. These records were co-created and reflected the social constructionist paradigm where reality is socially constructed. Personal recordkeeping, as both the activity and the product of that activity, was collaboratively derived through social interaction. “Rather than looking for an external reality the naturalist looks for internal realities – the sense-making and belief structures that order human existence and that exist only inside individuals.”<sup>382</sup> The ways in which each participant and I contributed to the construction of the research setting was unique.

I did not want to make assumptions. As the participants and I became more familiar with each other I also felt comfortable asking questions in order to clarify if I had understood or interpreted correctly more sensitive stories. The person, their contexts and the decisions regarding self and personal records were interrelated and situated. There are multiple contexts that a single person is engaging in at any one time. Some contexts may seem more obvious. Other contexts revealed themselves in the private lives of individuals as they navigated change. Creating the ritual of time and place, dedicated to telling and sharing personal stories, became a process of shared memory-making. The interpersonal events and the production of vignettes became a way of making explicit those shared memories.

#### **4.6.3 From vignettes to life book**

The vignettes as they were created and reviewed became parts of a corpus of personal stories and images. The intention had always been to leave, with each participant, a copy of their

<sup>382</sup> E. G. Guba and Y. S. Lincoln, *Fourth Generation Evaluation* (Newbury Park, CA: SAGE Publications, 1989), 137.

stories produced through this research. What I could not have anticipated prior to working with participants was the just how this collection would look and feel. These personal stories and the pages represented became powerful records of moments shared between the participants and me.

Each set of vignettes was personalised. Though the vignettes had evolved through reviews and iterations they were recognisable as the product of our encounters. Their design was simple. The paper pages were tangible and the book-like structure familiar and intuitive to use. I adjusted the font size to the needs of each participant for easier reading. I printed on heavier weight paper to make turning pages less fiddly. I personalised the template I used for each person's vignettes with a meaningful background image.

I decided to call this corpus of vignettes a life book. The life book could not be described as a biography or life story; it was not chronological, nor did it attempt to capture the person's history. The vignettes as separate pages meant that they could be changed, moved around and ordered differently through the review process.

In giving a copy of the life book to each participant I decided to maintain the functions of the book as something which was not fixed or finished, but rather representative of a point in time. The binding was a clear folder so that it was possible to see what this book was and who it was about. The first page included the name and a photo of the participant. The pages were inserted into the binding so that they could easily be added to, removed or replaced. Family members had expressed interest in pursuing these recordkeeping activities with participants. I provided a digital copy of the life book on USB which could be used as a template for further work.

These vignettes and the life books took on a life of their own. They were records created, as part of this research process, to address the personal as well as the recordkeeping concerns for each participant. These were *person-centred* records we created and used as tools for understanding and reviewing the person's perspectives. Each life book, within its pages, reflected the personal stories of the participant, their perspectives as a textual and visual representation. The content of the life books was personalised for aesthetics and usability. The vignettes and the life books were works in progress.

#### **4.6.4 Vignettes and life books: Co-creating products of research and data for analysis**

The vignettes and life books were both the products of this research process and data for further analysis as a work in progress. In essence the vignettes and life books were creative works, and the product of what was practice-led research.<sup>383</sup> In discussing my findings within this thesis I am reporting both context and reflexive commentary on the processes for co-creating these vignettes as a creative component of this research. I have included a participant

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<sup>383</sup> J. Hamilton and L. Jaaniste, "A Connective Model for the Practice-Led Research Exegesis: An Analysis of Content and Structure," *Journal of Writing in Creative Practice* 3, no. 1 (July 1, 2010): 31–44, doi:10.1386/jwcp.3.1.31\_1.

life book as an attachment to this thesis, and as substantial outcome of knowing and working with participants. This version of the life book is a working document in which I have included the participant's comments from the review process.

The vignettes and life books we co-created were also the data I analysed in this second generation grounded theory research. Importantly these vignettes were the voices of the participants located across the interviews in which the stories were shared and reviewed. Vignettes and their co-construction were an integral activity in this research. Co-creating vignettes was a way of moving from oral story to a physical representation. The processes were adapted to each participant and to reflect their personhood, personal contexts and situatedness. The results of using vignettes as process demonstrated that it was a powerful tool. It was powerful for creating shared understandings through reviewing the stories as content. We discussed the meanings associated with these vignettes as a physical construct. Based on these explorations we were able to make decision regarding how the vignettes could be shaped and what needed to be represented and how. The personal implications of these decision stories were then able to be explored.

## **4.7     *Reflections on Ethical Wayfinding While Working with People and Records***

Throughout the archival research processes of co-creating the records with the participants, I found that the process I call 'ethical wayfinding' was absolutely essential and central to the research and archival process. As a researcher I had not only a role but was creating relationships with participants which contributed to the research and to the participants own personal contexts. I was progressively learning and responding to people as much as they were learning and responding to me.

Importantly I was incorporating the learnings to innovate in research practice as the study progressed. Ethical wayfinding was what I would describe as a consciousness of what was happening for participants in relation to the roles I played and relationships we were nurturing. I introduced techniques to address my concerns about understanding explicitly the perceptions of participants which included: personal mapping and creating vignettes that could be shared and reviewed.

I attended to the participant needs and followed their cues. This was a significant factor in practising ongoing consent throughout the interviews. I was making decisions about research in relationships with participants to understand their willingness to participate and those salient stories of situated meaning we explored in our conversations. I developed ethical processes for creating personal records as a co-construction. The archival contribution is these ethical processes and techniques for ethical wayfinding were effective in this project while working with people with early dementia and co-creating records to support their choices and memory.



## 4.8 Conclusion

In this chapter I have presented results from the grounded theory research with regard to the processes and techniques of co-creating person-centred records with the participants. After introducing each of the participants, the findings were presented in relation to ways and processes for exploring the personal and situated contexts of the participants. This was followed by the findings in relation to the processes that were used in co-creating the participants' vignettes as personal records. In addition, the practice of ethical wayfinding was identified and discussed. This second generation grounded theory methodology and qualitative research techniques described in Chapter 3 were central to the methods of inquiry into the processes of co-creating the personal record with the participants in the study.

The findings begin to answer the aim and questions of this research by highlighting the importance, to participants in their current contexts, of person-centred stories and personally meaningful records in constructing identity and supporting memory. These stories and records, for varying reasons were present, absent or lost to the person in their immediate environment. Importantly the stories of self that participants told were oral records and not recorded elsewhere. The interviews and vignettes were the stories of self. The telling of stories was a powerful medium for understanding how these activities support memory, identity and personhood. The co-creation of vignettes and their review with participants recorded these stories to facilitate studying how meaning was co-constructed.

Throughout the weeks of interviews, I developed systematic processes and an innovative repertoire of methods and techniques for working with participants with dementia and records. The methods and techniques were progressively adapted to address the specific needs of each participant; for understanding their unique contexts and experiences of records of self. The practices I developed for co-creating vignettes were based on knowing the person respecting their voices and perspectives. These vignettes became central tools for understanding how records support memory, identity and meaning.

This chapter claims innovations in working with people and their data to co-create person-centred records. These records represent stories of self and identity. They were selected and co-constructed in partnership with people who have early stage dementia and they are a process and a production. As results in a grounded theory process, these findings about processes that were effective are substantive contributions to archival theory and practice. In the following chapters further results are presented and discussed.

## 5 Findings 2: Analysing Shared Memory-Making and Co-creating the Person-Centred Record

### 5.1 *Introduction*

This is the second of three chapters in which I present results of this second generation grounded theory study in relation to open, in vivo and selective coding. In this chapter I share the outcomes of analysing the context of co-creating content and exploring the meaning of the vignettes with the participants. The findings revealed that the co-creation of records was integrally linked with the interpersonal processes implemented in their creation. These processes supported developing relationships and sharing knowledge of self.

The chapter begins with an introduction on how the research challenged dominant perceptions regarding personhood and the person with dementia. I explain the analytic processes which led to the development of vignettes through thematic coding and key conceptual categories. I reveal the findings of selectively coding to the core code the person-centred record as a process. I also discuss the use of mapping as a second generation grounded theory technique, consistent with the postmodern underpinnings of the methodology, for analysing complex contexts and data. This chapter is structured into four key sections. Within each section I discuss the findings in relation to:

- Section 5.2: Working with people and their data: Personhood as the theoretical approach and person-centredness as practice.
- Section 5.3: Ways for thinking about and knowing stories as voices and unique perspectives.
- Section 5.4: Analysing the records co-created in this research to understand context and meaning.
- Section 5.5: How the co-creation of person-centred records established shared understandings of the participant, their personal stories and the vignettes as records.

Creating personally meaningful records required analysing the interviews as they were experienced, transcribed, heard and interpreted. Analysis involved a detailed study of the many contexts which were informed by the relationships each person had with him or herself and the world around them. The personal stories participants told were constructed into vignettes and then incrementally reviewed with the participants to understand the patterns and complexity of meaning and relationships. Analysis also involved reconstructing this new data, and expanding the context of findings as new knowledge.

## **5.2 Theoretical and Practice Influences**

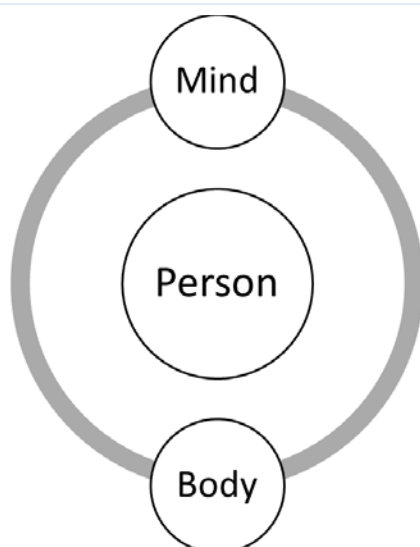
The theoretical sensitivity I developed in this research regarding the theories of personhood influenced both the approach I took to working with people, and the ways in which I analysed and interpreted their data. These theories of personhood did not prescribe practices for working with people with dementia. Rather, they highlighted the need to develop in-depth and rich knowledge of the whole person and their situated contexts as they changed and evolved. The findings in this section are reported with respect to how person-centred processes, practices and coding were developed in order to explore individual perspectives and unique contexts. These are discussed using the following headings:

- Personhood as a philosophical approach to working with people
- The core code of person-centred record was the processes and practice
- Mapping as technique for analysis of data, interpersonal processes and co-creating records.

### **5.2.1 Personhood as a philosophical approach to working with people**

The findings of the previous chapter demonstrated how personal storytelling and co-creating records were powerful processes for sharing highly contextual knowledge with the people in this research. In this chapter I focus the analysis on understanding these research activities and the human relationships to the records as they were being co-created and used. What was the meaning of those records as they were being co-constructed and in the vignettes we created? Through the creation and review of vignettes the participants and I were incrementally exploring those significant narratives and their meaning. This level of analysis allowed me to explore the significance of these activities and their relationship to personhood and records.

I explored in Chapters 2 and 3, through the review of literature, the contestation of dichotomous views of being human in which there is demarcation between mind and body. It was therefore a conscious process, throughout analysis of the data, to reflexively consider the unity of self through continuity of mind and body rather than as separate dimensions. The codes of mind and body were early concepts drawn from literature which acted as a reminder, to me as the researcher, to always consider the person as a whole (see Figure 21). I was mindful as a researcher that I was also actively challenging perceptions of the person with dementia as losing their identity or being another person when affected by cognitive changes associated with dementia.



**Figure 21 A holistic view: contesting dichotomous views of being human**

In Chapter 4, (see Section 4.5) each of the participants described concerns regarding how a diagnosis of dementia had changed the way they believed others perceived them. I did not want to make assumptions regarding the nature of personhood, which is that unique individual experience of memory and identity. Dementia was part of each person's context but it was not the person.

This second generation grounded theory study and empirical research was designed to explore concepts as they were being shaped and experienced within the context of their use. We were co-creating records of personal meaning. I wanted to understand how these records were representative of personhood and the affordances of this record creation process which made them person-centred.

In the subsequent sections I will explain the codes which were developed as categories and their properties as dimensions.<sup>384</sup> The codes were the product of analysis in which I sought to understand how the records we co-created were stories of self and therefore person-centred. What were the dimensions and properties of these records not only as a product but in the relationships participants had with the record and the story as content? Exploring personal stories and co-creation of person-centred records allowed me to understand how our stories and therefore the records created from these stories represent personhood.

<sup>384</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015.

### 5.2.2 The core code of person-centred record was the processes and practice

A core category, in grounded theory research, is conceptualised and selected by the researcher during the processes of analysis and coding data. The core category “encapsulates and explains the grounded theory as a whole...further theoretical sampling and selective coding focus on actualizing the core category in a highly abstract conceptual manner.”<sup>385</sup> Through the research processes reported in Chapter 4, as well as the phases of analysis and coding, I identified two core concepts and categories in relation to the records we were creating: personhood and person-centred (explained in Chapter 2) seemed to capture the intent of the research and the processes for co-creating records. These concepts also reflected the type of stories being shared by participants.

The concept of the person-centred record was emerging through the analysis of the records we were creating and exploring; through a process of focusing on the perspectives of the participants and how they were constructing personhood with me as the researcher. In co-creating vignettes it was my intent that the research processes supported staying close to the participants in terms of the knowledge we were developing. I used systematic techniques for checking that both the vignettes and their constituent stories and images represented personal perspectives in a way that made sense for each individual.

I was seeking to understand participant interactions as highly situated contexts; their stories and images were used as content for the vignettes as well as the meaning associated with each of the vignettes we created. Exploring personal stories and co-creation of person-centred records allowed me to understand how our stories and hence the records created from these stories represent personhood.

### 5.2.3 Mapping as a technique for analysis of data, interpersonal processes and co-creating records

In this research situational mapping was used to explore the “complex situations of inquiry” without over simplifying the knowledge being created or its representation.<sup>386</sup> This type of mapping supports developing “thick description”<sup>387</sup> and analyses of research contexts to “elucidate complexities – the key elements and conditions that characterize the situation of concern in the research project broadly conceived. Situational analyses can deeply situate the research individually, collectively, social organizationally and institutionally, temporally, geographically, materially, culturally, symbolically, visually, and discursively.”<sup>388</sup>

When undertaking the layers of data analysis, I was conscious of Clarke’s challenge to map when working with complex situational contexts as described in Chapter 3. The mapping

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<sup>385</sup> Ibid., 12.

<sup>386</sup> Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*, xxii.

<sup>387</sup> J. R. Fosket, *Breast Cancer Risk and the Politics of Prevention: Analysis of a Clinical Trial* (San Francisco, CA: University of California, 2002),

[https://books.google.com.au/books/about/Breast\\_Cancer\\_Risk\\_and\\_the\\_Politics\\_of\\_P.html?id=QIB9NwAA CAAJ&redir\\_esc=y](https://books.google.com.au/books/about/Breast_Cancer_Risk_and_the_Politics_of_P.html?id=QIB9NwAA CAAJ&redir_esc=y).

<sup>388</sup> Clarke, “Situational Analyses,” 553–554.

provided ways of viewing all the codes and categories as they accumulated. Considering the postmodern nature of this research, mapping served an important tool in visualising themes, codes and categories and the multiple possible relationships they had with each other.<sup>389</sup> I describe the identified codes and categories as categories of meaning. Expressions (Categories) of personal meaning described in the vignettes

Figure 22 is a situational map specific to a single participant Jean. It is illustrative of the type of mapping espoused by Clarke where “generating sensitizing concepts and theoretical integration...is an ongoing process.”<sup>390</sup>

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<sup>389</sup> A. Fontana, “Postmodern Trends in Interviewing,” in *Handbook of Interview Research: Context and Method*, ed. J. F. Gubrium and J. A. Holstein (Thousand Oaks, CA: SAGE Publications, 2002), 161–75.

<sup>390</sup> Clarke, *Situational Analysis: Grounded Theory After the Postmodern Turn*, xxxiii.

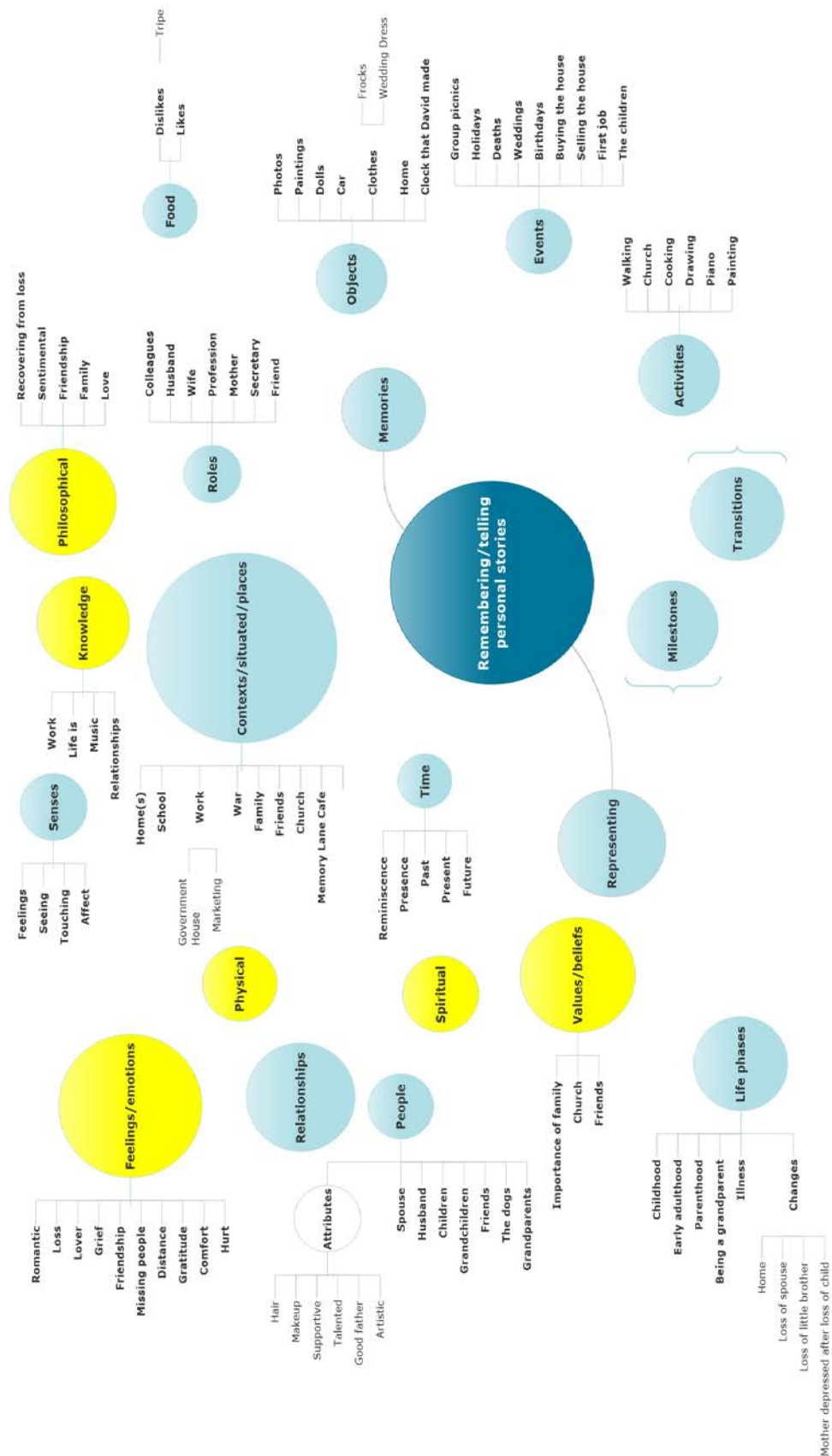
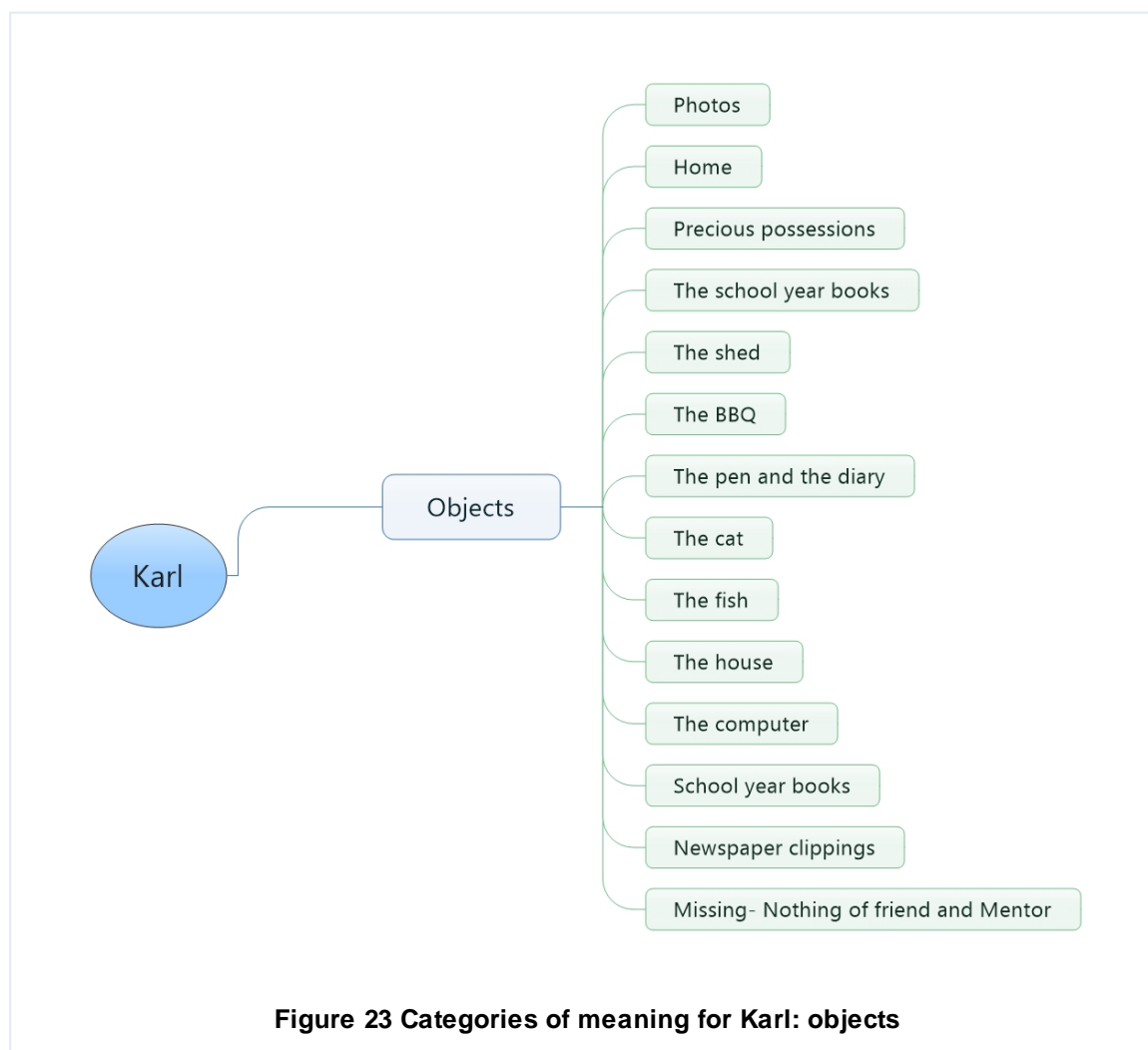


Figure 22 Categories of meaning for Jean

Each individual map was begun in the initial coding of: the personal stories recounted in the interviews and the vignettes as they were constructed. Figure 23 is an example of the analysis and mapping of data created with Karl.



The same mapping process was conducted for each of the three participants and then merged into more comprehensive maps as illustrated in Figure 24 that “more fully takes into account the complexities of postmodern life”.<sup>391</sup> It is important to note that the terms represented and used are multi-relational. Codes, categories and themes were defined by the content of the story to which they pertain. These codes are signifiers in that they pointed to; a process, something, someone, an event, a time or place in a personal story. These signifiers behave as generic terms which are characteristic of a group or class of things.<sup>392</sup> These signifiers become abstract concepts when mapped in relationship to each other.

<sup>391</sup> Ibid.

<sup>392</sup> “Generic – Definition of Generic by the Free Online Dictionary, Thesaurus and Encyclopedia,” accessed April 27, 2014, <http://www.thefreedictionary.com/generic>.



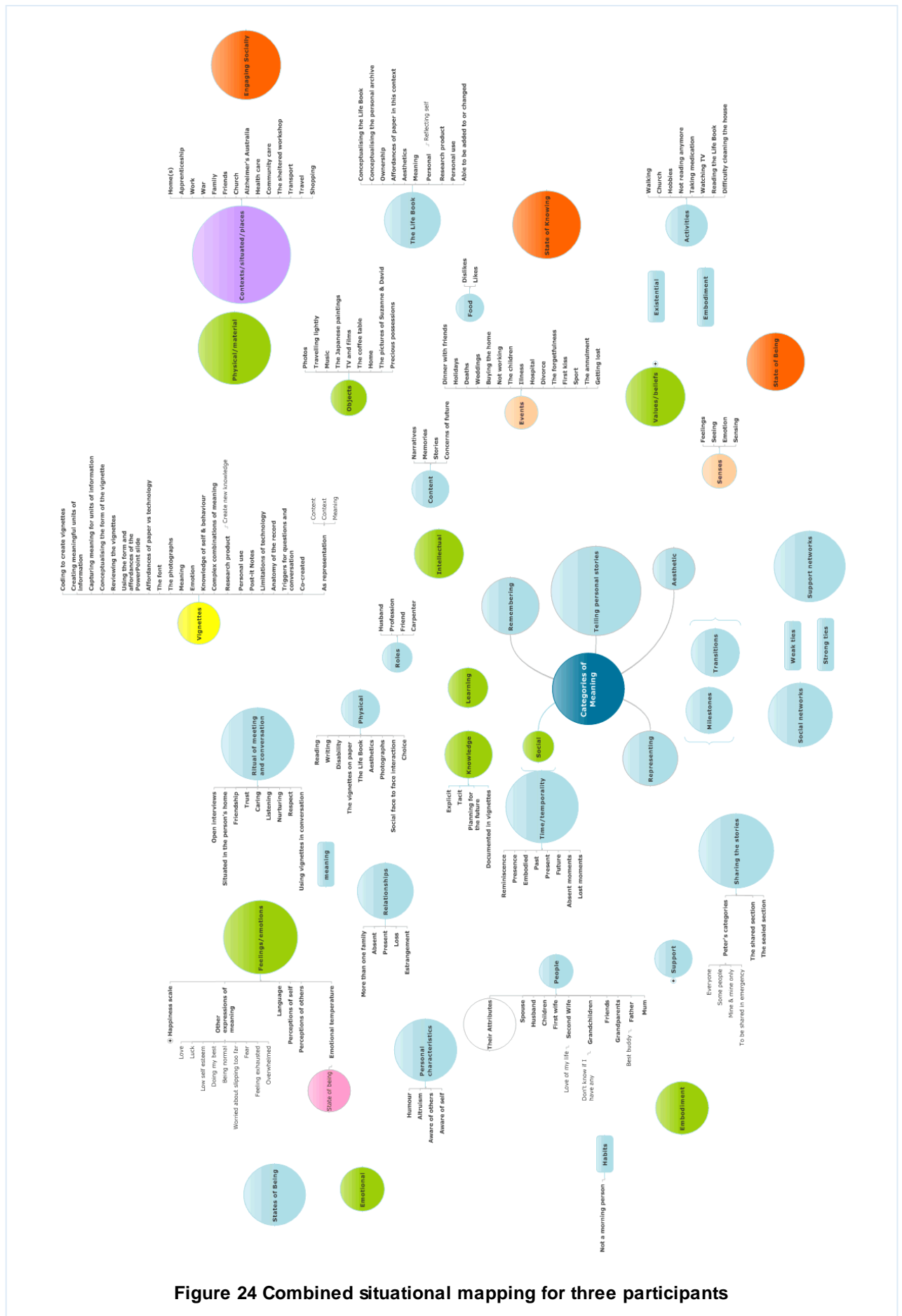


Figure 24 Combined situational mapping for three participants

The findings in this section reported how knowing a person as an individual, and as part of a broader context which included personal recordkeeping, was underpinned by developing knowledge of personhood in theory and in researcher practice. Knowing a person and their own expressions of personhood required understanding their unique perspectives of self, in relationship to others as well as their records. Mapping as a research activity was instrumental in representing and making-sense of these complex knowledges and participant data. Mapping as a tool facilitated discussions with participants in order to see the whole person and their perspectives within their broader as well as situated contexts.

### **5.3 Ways for Thinking About and Knowing Stories as Unique Perspectives**

As the researcher, I had to find ways to challenge my own perceptions and look beyond the obvious to hear participants' stories as unique perspectives and in person-centred records. Understanding the meaning associated with stories or records was not always explicit. As an activity, storytelling was conducted in the context of relationships between people. The quality of those experience was dependent on my ability as a researcher and participant in the storytelling to engage with participants in their world as they knew it. In this section I present the findings in relation to how I engaged with participants in storytelling and co-creating records as representations of self. These findings are reported in the following sub-sections:

- Memo: A metaphor for thinking about what was absent in the records
- Shared memory-making: Stories, vignettes and life books
- Storytelling and shared memory-making were performative
- Memo: Empathy as research practice.

#### **5.3.1 Memo: A metaphor for thinking about what was absent in the records**

Scientists continue to be surprised by new and evolving knowledge regarding the substance and nature of space. What sometimes seems empty is not truly so. In reality, what seems to not exist can have incredibly powerful influences on those things around it. Burchat explains how physicists know that ordinary matter, dark matter and dark energy exist.<sup>393</sup> Ordinary matter is a term for “the substance that makes up all observable physical objects”.<sup>394</sup>

Matter makes up only a few percent of the universe and is detected because it can be measured and evidenced through the electromagnetic spectrum. Dark matter and dark energy are not visible and not detectable on this spectrum. They are instead evidenced by their gravitational effect. Dark matter does not interact with the electromagnetic spectrum but we know it exists and even dominates by its pulling effect which draws matter closer together.

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<sup>393</sup> P. Burchat, *Patricia Burchat: Shedding Light on Dark Matter*, TED Video. Filmed, 2008, [http://www.ted.com/talks/patricia\\_burchat\\_leads\\_a\\_search\\_for\\_dark\\_energy](http://www.ted.com/talks/patricia_burchat_leads_a_search_for_dark_energy).

<sup>394</sup> “Matter – Wikipedia, the Free Encyclopedia,” accessed May 7, 2014, <http://en.wikipedia.org/wiki/Matter>.

Physicists believe that dark energy, which is even more elusive, creates distance and space between matter.<sup>395</sup>

The physics of matter, light and energy is a thought provoking metaphor for the person as well as the record as a social construct. We see and recognise things because they fit within a certain spectrum of perception and understanding. This raises questions regarding how and what we know. How can we learn about what is not immediately present or may be unknowingly distorted? How can we become sensitive to what is elusive and may not fit within a defined category?

Storytelling in this research gave form and substance to personal events which had sometimes not been told or recalled from the past. The process of creating vignettes was like observing matter and light but not always understanding exactly how they were positioned in relation to each other. The major breakthrough for me was observing just how much a person could be affected by their personal narratives. It was realising that emotions and feelings are the way human beings experience the world and their sense of self in relation to others. Stories as they are told may seem unique events but the trigger for their telling, as with rays of light, may be related to something not within the realms of observation.

### 5.3.2 Shared memory-making: Stories, vignettes and life books

Thematic analysis and the first levels of coding resulted in incrementally assembling a selection of the stories shared by participants within the context of the interviews. Over the eight week-interview period the participants and I constructed a collection of approximately 60 vignettes. What may have seemed conspicuous to me in conversations with participants was not necessarily the way others perceived things to be. At times I found myself uncertain of how to decipher what a participant had said. It might have been that the words were not clear or the meaning not explicit. Co-creating personal records was a collaborative technique for explicating perspectives, knowledge and decision-making. What are the decisions made in the context of the research and more importantly what are the dynamics which influence the making of those decisions?

In the case of the participants in this research, who are living with dementia, they were each confronted by the diagnosis as well as the disease. When working with Karl and his stories, I was challenged more frequently, due to the difficulty he had with remembering names of the subjects in his stories. There were transcribed stories which did not always adequately represent the stories that he was trying to tell. The words, the narrative threads would get tangled. At times the connections between phrases or story parts were lost in a pause of trying to remember. I asked Karl, how he felt memory loss had impacted on what he was remembering.

*Karl: Oh I can remember those, can't remember people's names very well I mean those blokes that I worked with for 20 years, and even, I still, I go to a luncheon, it's a racing combined racing luncheon*

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<sup>395</sup> Burchat, Patricia Burchat: *Shedding Light on Dark Matter*.

*but there are some of the original ones still around, of the 16, there were I think there was only three of the original 16, there were only three at the, they had the 50 year luncheon in March and one of the blokes, the bloke who's a bit older than me, well up in his 80s, might be 87, but he was older than me but that didn't make any difference because he still used the same system.*

*And wherever he went you could tell because when those blokes left the branch they'd set up and they went to a bigger one, that's what they would use. We used to set them up and then we'd go off, and you were supposed to go back and help them if they got in trouble, because they didn't have enough people to put one... 'cause they opened on the first day they were [supposed to] open 16 and they opened 14, two they didn't you couldn't get council permission, one was Essendon.*

As illustrated in the above excerpt, though Karl could at times not recall a name or the dates he was also conscious of not being able to remember. The absent names were like stumbling blocks. I could see he knew who he was talking about. These were shared interactions and it was my challenge to support Karl in his recounting of stories.

Working with these participants in the context of dementia was particularly rewarding. The processes for sharing stories through remembering and conversations was a powerful process. We were together able to work with individual challenges in communicating. The storytelling process enabled conversations about dealing with memory loss. Even through these difficulties participants were able to retrieve in different way the gaps their remembering.

### 5.3.3 Storytelling and shared memory-making were performative

Storytelling and shared memory-making were performative and acts of agency. It was in the course of the human encounter and the evolving relationship that stories and memories of life were shared. These interpersonal processes were pivotal to how the participants, recordkeeping activity and product were created as well as understood. Co-creating person-centred records was both a human activity of shared memory-making and records as the product of this activity. The quality of this research project depended on the character of relationships developed between researcher and participants as well as the richness of the data.

Getting to know a person in a constructed research context took both skills and sensibility. Being an effective qualitative researcher required being able to elicit, listen for, see, sense and thereby develop those codable moments.<sup>396</sup> Identifying person-centred stories was often about finding the extraordinary in the ordinary. I discovered how each of the participants in their situated contexts was unique and influenced by social forces. As I got to know the person I was interviewing, a story which may have at first seemed factual was actually inspired. I describe these stories as faithful, if sometimes understated, in just how they related to the personal narrative and personhood. These stories bubbled up through our conversations. Through their telling they wove themselves into the fabric of my own experience and memory. Knowing someone means becoming familiar with their stories. If each telling of a

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<sup>396</sup> Boyatzis, *Transforming Qualitative Information: Thematic Analysis and Code Development*; R. K. Yin, *Qualitative Research from Start to Finish* (New York: Guilford Press, 2010), <http://books.google.com.au/books?id=RvRze7ZnbqMC>.

story is a socially constructed event then the story is related to the situated context of that telling.

The narrating of stories were records in themselves. In co-creating and studying the vignettes we, the participants and I, were also evidencing some of what that experience embodied. It was this experience that I interpreted. It was a reflexive process. As explained in Chapter 4 (see Chapter 4 Section 4.6), I had purposely waited to commence the review of vignettes as I did not want our conversations to be focused on only what had been previously told. There was space to allow the engagement and conversations to evolve. It also took time to familiarise myself with the participants and understand what was not recorded in the transcripts. What was absent in the research records was important in making decisions.

### 5.3.4 Memo: Empathy as research practice

Empathy was an approach to working with participants which influenced my practice as a researcher. As each participant shared their stories of life, I became conscious of their unique concerns and how this impacted on their perception of self. Brown defines “empathy as the skill or ability to tap into our own experiences in order to connect with an experience someone is relating to us.”<sup>397</sup> Empathy is something that we don’t speak about much in the world of research. As with many of what are considered the softer personal skills, I found that there was very little advice for the researcher regarding how important it is, to try and understand what it is like to be in the situation of another person.<sup>398</sup> As the researcher I was trying to straddle the worlds of the participant in light of my own experience. Whether from their own recounting of accounts, past or present, oral or written, *we* were moved by these stories. Wiseman’s four defining attributes of empathy in practice are: “See the world as other sees it, don’t be judgemental, be understanding of another’s feelings and communicate the understanding.”<sup>399</sup>

These attributes of empathy constituted important characteristics for reflexive research practice when working with people but also in interpreting their data. In the practice of this research, sharing, recording and studying personal stories were techniques for trying to see the world as the participants saw it. My role was not to judge but interpret to the best of my ability and through communicating with each person regarding how they felt about the recorded stories. I was trying to understand their perspectives.

These findings demonstrate how in-depth interviews and personal storytelling were integral to understanding participants’ unique perspectives. Importantly, personal storytelling was the act of making explicit memories and stories of self in ways that could be shared with others. These storytelling activities, for externalising the personal experience, revealed how the

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<sup>397</sup> B. Brown, *I Thought It Was Just Me: Women Reclaiming Power and Courage in a Culture of Shame* (New York: Gotham, 2007), 32–33. Kindle Edition.

<sup>398</sup> Some useful resources have been created by academics to try and explain empathy as it is often confused with sympathy. For an overview of these concepts see B. Brown, “Brene Brown on Empathy,” December 10, 2013, <https://www.youtube.com/watch?v=1Evwgu369Jw>.

<sup>399</sup> T. Wiseman, “A Concept Analysis of Empathy,” *Journal of Advanced Nursing* 23, no. 6 (June 1, 1996): 1165, doi:10.1046/j.1365-2648.1996.12213.x.

storytelling context and the associated meaning were co-constructed and the product of interpersonal processes as well as acts for co-creating vignettes as records. The implications of these findings highlight that both the participants and the researcher were active agents in the personal storytelling and co-creating records. The relational nature of these activities depended on the researcher's ability to empathise by trying to understand each participant's unique experiences.

## **5.4    *Reviewing and Analysing Vignettes to Explore Their Content, Context and Meaning***

Co-creating vignettes as records of personal stories was a technique for making explicit the stories of self. These vignettes provided tangible ways for exploring person-centred records as representations, and for their tacit as well as explicit meaning. This section details the findings in relation to the analysis and review of co-created records through their content, context and meaning.

In exploring vignettes for content, context and meaning, it was not possible to revisit and review every piece of these complex personal narratives with the participants. The stories were progressively created and refined as story devices. As explained in Chapter 4, reviewing the vignettes with participants began around the third week of interviews. There were prior weeks of interviews and analysis of data to help me distil those stories which were recursive and seemed to embody meaning – even if it was not always clear what the meaning was or for whom.

The participants and I were socially constructing knowledge of shared language and nuances in the way we spoke. Social constructionists work from the premise that concepts such as words, objects or in this case records have no intrinsic meaning. Meaning is what we give to a concept and this is a shared process.<sup>400</sup> The stories became part of a repertoire between participants and researcher. As we met over the weeks, I noticed how my own engagement with participants and stories was transformed. I knew some of these stories so well that in a lost moment where the words were absent I could simply say the missing name and the storyteller would continue. This helping to fill in the gaps in narrative has been described as a way of assisting people with early or moderate dementia.<sup>401</sup>

Co-creating a record, which represented the story told, provided a tangible product which could be checked and evaluated with participants as well as a process for sharing meaning. In this context where stories were complex and deeply entangled with other stories, we could explore at a more granular level, the plurality of content and meaning. I used systematic layers of analysis to study the contexts and content of personal storytelling in order to understand the meaning associated with these stories and the records we were co-creating. There were

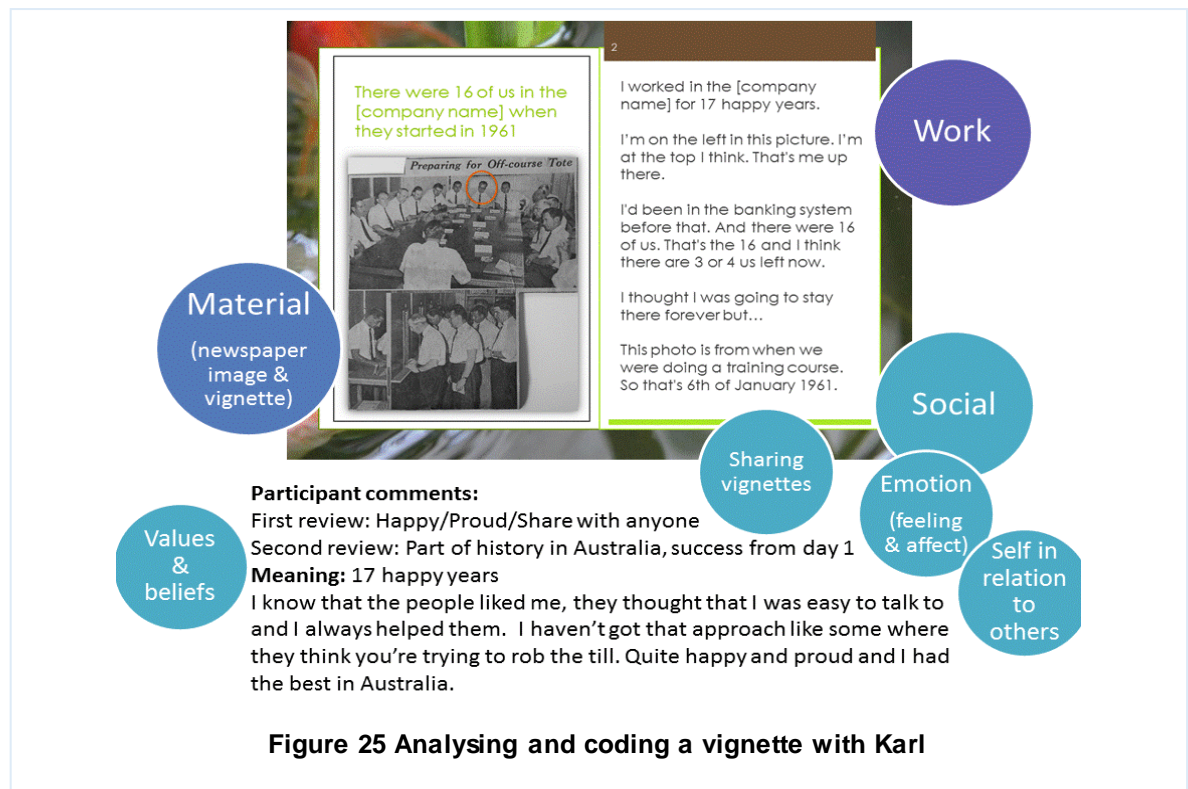
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<sup>400</sup> Burr, *Social Constructionism*.

<sup>401</sup> C. Baldwin, "Narrative and Decision-Making," in *Decision-Making, Personhood and Dementia: Exploring the Interface*, ed. D. O'Connor and B. Purves (London: Jessica Kingsley Publishers, 2009). Kindle Edition.

two key analytical processes being undertaken. Figure 25 illustrates the review and coding process of the vignettes. The vignette's content was coded as text, image and record. Coding this vignette revealed:

- Karl was reflecting on this story in association to a newspaper cutting of him as a *material* object.
- This is story of *work* in which Karl is reflecting on himself *socially* in relation to other *colleagues*.



The review of a singular vignette in different interviews was the retelling of a story into a new time and context. Where possible, as was the case with this vignette, the review was undertaken on two occasions. In the first review Karl expressed *emotions*; he was *happy* and *proud* of this story and event. It was a story that he would be prepared to *share with anyone*. On the second review Karl described the story as being “part of history in Australia, success from day one”. This story represented 17 happy years. Of particular interest here is that Karl is comparing himself to others in terms of his *qualities* as well as the *values* that he holds and practices.

This retelling revealed that participants adjusted their voicing of stories of self in relation to other people and the broader context. They made explicit comments regarding the sharing of stories in relation to how those stories were received by others. Patrick was comfortable telling stories of self which he had not previously shared with his wife as described in Chapter 4. Karl was well aware of how he repeated stories and the effect of this on his family.

*Karl: Well I find that you repeat them, my family get sick of it.*

On a number of occasions Jean's family became part of the storytelling event. With each person who engaged in the storytelling event, the voices as stories and perspectives became even more complex and recursive. For me creating the vignettes was a way of reflecting and checking with participants what they were trying to impart to me.

Memo: Dementia is a cause of difficulty in communicating but, as I reflect on my own language as I try and explain concepts and processes to participants, I am conscious that the words do not always come out 'right'. In speaking or writing we are externalising or making explicit what is often tacit knowledge and this can be difficult to convey. This is especially important when considering that my understanding of concepts was emerging and evolving through this research. I was testing my own concept development as it was being defined in this context.

It was interesting that even though Karl had difficulty in articulating parts of language, he seemed to find it easier to fill in the gaps and correct his own stories when reviewing the printed versions of the vignettes. In this excerpt below Karl is correcting the vignette.

*Karl: That should be 17 years. Well you've got 17 down there. Ten in the...[pauses] Yeh, With [name of company] Later on. With [name of company].*

The vignettes acted as scaffolding so that Karl could make connections between concepts and narratives. The vignettes also behaved as scaffolding of those narratives we shared. Stories as voice are so fragile; they depend on the abilities of a person to communicate and another to understand. How could I interpret voice and the implications for this? These are questions that go to the heart of postmodern and poststructural readings of voice, truth and meaning. Traditionally, there has been a privileging of voice in qualitative research.

[Voice that] is heard and then recorded, coded, and categorized as normative and containable data...How do we go about working the limits of voice? And why should we be engaged in such a practice? How does putting privileged understandings of voice under poststructural scrutiny result in a positioning of voice as productive of meaning – as excessive and unstable voices that surprise us, both pleasantly and uncomfortably, with previously unarticulated and unthought meanings? We assert that in our zeal as qualitative researchers to gather data and make meaning, or to make easy sense, we often seek that voice which we can easily name, categorize, and respond to. We argue that a more fertile practice, and one that is advocated in this collection by the authors, is to seek the voice that escapes easy classification and that does not make easy sense. It is not a voice that is normative, but one that is transgressive.<sup>402</sup>

As is reflected in this chapter the processes for knowing and understanding participant voices were fraught and required that I seek out those voices and meanings which were less easily articulated. After each interview I began the transcription and review of recordings both audio and photographic. These complex conversations were embedded with stories of *people, events, places* and *objects* with traces of *affect, feelings* and *emotion*. Table 11 lists examples of those

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<sup>402</sup> Jackson and Mazzei, *Voice in Qualitative Inquiry: Challenging Conventional, Interpretive, and Critical Conceptions in Qualitative Research*, 47.



open and in vivo codes, in relation to people, events and places, which I defined through analysis and coding of the vignettes and in light of the situated interview context.

**Table 11 Categories of meaning: People, objects, events and places**

Codes and Categories			
People	Events	Context/situated places	Objects
Spouse Parents Children Grandchildren Friends Nick the cat Sister Brother Family	Studying Deaths Getting married The children Illness Being in hospital The forgetfulness Sport Building the house The driving test Losing the drivers licence Work	Home(s) TAFE Work War The depression Family Friends Fell out with the church Alzheimers Australia Health care Transport The car Horse racing	Photos Home Precious possessions The school year books The shed The BBQ The pen and the diary The cat The fish The house the computer School year books Newspaper clippings Missing-Nothing of [name of person] Coffee table Films Music The wedding dress The china dolls Paintings The dog The clock

Over the weeks, as I listened to the audio-recording and transcribed, I relived the words we had spoken in the interview process. I was aware of the pauses where no-one said anything audible. I also began to remember the faces that people pulled when they made a joke or were moved by something they had said. I was developing memory; an aural and visual repertoire of that person that was not captured anywhere else. I developed sensitivity to the tone of their voice when recorded which distinguished the humorous from the serious, the uneasy from the simply thinking or trying to remember. I realised throughout that process just how all-consuming this activity was and would continue to be. It was *affective*. The voices were impregnated in my memory. I was reminded of my own life experiences and considering how I would feel about this process if I were the participant being interviewed. I was affected by the stories and I was making decisions and choices about how these people and stories would be represented through the recording of this research.

A single person had many voices through many perspectives. In between the recorded voices there were also silences; we were in the same room at the time of the recording but there was no evidence of the people recorded. It was only because I had been there that I could recount with authority who was there. As I became more familiar with the person I was able to ask

more questions to clarify what was not explicit or not spoken. The vignettes would retrieve some of those qualities. It would allow a fragment of that narrative event to be captured.

I realised within those first few interviews that the way we feel or the way we are *affected* by our stories are not always explicit or tangible. They can become veiled by the narrative and even how I as the researcher felt when I heard the story. I would remember the meaning and affect as well as the details of the story.

The findings in this section revealed that co-creating of person-centred records was both a way for representing and reviewing stories of self with participants. By making these stories explicit and implementing an incremental review process, I was able, as the researcher, to enter into each person's world. I was able to analyse the stories for participants' categories of meaning; that is the significance of the story as content, the associated meanings and the affective nature of the vignettes as representations. The rest of this section articulates the findings with regard to experience of co-creating person-centred records and the categories of meaning. These findings are presented in the following sub-sections:

- Affect, feeling and emotion
- The ritual of conversation and connecting with people
- Physical relationships were material and social
- Relationships: Temporality, time and place
- The embodied experience

#### **5.4.1 Affect, feeling and emotion**

The encounter between human beings was a complex process and narrative events were subjective constructions. Even though the telling of a story had elements which were tangible and seemingly concrete, those elements remained abstractions until the specificity of the instantiated narrative was understood. I had initially noticed emotions in both the language and the physical expression of Patrick my first participant. Sometimes the emotions were explicit in that a word was said or the effect of an event was reflected upon. Other times, as demonstrated in Chapter 4 the person and their storytelling were imbued with feelings associated with how they were affected by that event.

It was this finding that led me to explore affect, feelings and emotion as important codes and qualities of how participants experienced co-creating person-centred records. Though the conversations and data were rich with what seemed like sometimes simple narratives they were embodied with meanings and feeling. I observed each person's use of language and began to ask them questions regarding the emotional meaning of their stories. As demonstrated in Table 12, I found that the language participants used to communicate emotions and feelings was diverse.

**Table 12 Categories of meaning: Affect, feeling and emotion (1)**

Codes and Categories	
Love	Big decision
Happy	Somewhere in-between proud and happy
Proud	Loved the challenge
Very proud	Upsetting
Very Happy	Oh yeh, happy great
Part of life	Reminds me of what I know
Realised ability/how smart I was	Proud to be his son
Part of my education	A hopeless case
Important	Tried our best
Enjoyable	Disappointed that we failed
Made me achieve more	Repeating things drives me nuts
Pleased and lucky	Always a challenge
Didn't feel safe	Lucky to get someone so great—Wife

In the context of storytelling, participants spoke of how they felt. Patrick was able to articulate, verbally and with relative ease, a repertoire of emotions using the words that best expressed the ways that he feels. Discussions with Karl regarding the emotional impact of individual stories and vignettes encouraged him to make explicit the way he felt about particular events he described. While I found it challenging to explore descriptors of emotion with Jean, her stories were explicit narratives in which she described the way she felt e.g. depicting herself as emotional and sentimental. Emotions were always related to the circumstances or the event being communicated. I looked deeper into participant stories for expressions of emotion and the literature for knowledge of what this finding meant.

Though there were many ways of defining emotions in the existing literature through constructing complex psychological frameworks, the focus of this second generation grounded theory research was firstly recognising and acknowledging the ways that each participant expressed emotion as a signifier of meaning.<sup>403</sup> Emotions were those terms easily recognisable such as love, happy and proud. There were gradations of these common terms of emotion such as *very* proud and *very* happy. Participants were appraising their stories in the context of our conversations revealing how they perceived themselves and in relation to others.

Emotion is closely related to affect. Identifying affect and its impact was an important observation. Affect is that which connects us to the world when we affect something or are affected. “Affect is what sticks, or what sustains or preserves the connection between ideas, values, and objects.”<sup>404</sup> “To be affected by something is to evaluate that thing.”<sup>405</sup>

<sup>403</sup> The term emotion is embraced by philosophical, psychological and sociological discourses, and overlaps with affect and feeling; the discrete yet somewhat overlapping disciplinary paradigms influence the definition, description and function of these concepts.

<sup>404</sup> S. Ahmed, “Happy Objects,” in *The Affect Theory Reader*, ed. M. Gregg, G. J. Seigworth, and S. Ahmed (Durham, NC: Duke University Press, 2010), 29, <http://books.google.com.au/books?id=b10udWQii48C>.

<sup>405</sup> *Ibid.*, 31.

Participants used unique linguistic expressions to evaluate stories and describe how they felt about the story being shared. They were not only telling their stories but reflecting on those narratives and providing insight into why they were meaningful. There were some expressions of meaning such as love, happy and proud which were more obviously identifiable as feelings or emotions. There were also many more nuanced expressions of meaning as listed in Table 12. The language participants used reflected more than a scale of emotions but rather complex appraisals of relationships to *self*, other *people*, *objects* and *events*. Describing the properties of these codes in relation to co-creating records Table 13 revealed emotions are something that we do; they are acts shared in relation to other people.<sup>406</sup> Participants used some highly nuanced language when expressing emotions.

**Table 13 Categories of meaning: Affect, feelings and emotions (2)**

Codes and Categories	Properties
Affect Feelings Emotions	<ul style="list-style-type: none"> <li>• Sensing and expressing feelings, emotion and affect</li> <li>• Unique and shared expressions of meaning</li> <li>• Language was nuanced</li> <li>• Reflecting perceptions of self and others</li> <li>• Relationships to others and records of self</li> <li>• Expressing meaning: explicit &amp; social</li> </ul>

The codes of affect, feelings and emotions in this research captured the many ways that participants *experienced* as well as conceptualised the meaning of their stories and vignettes in relation to self and others. This was the broadest category and illustrated diversity in how meaning was expressed. In the case of this study where we were co-creating person-centred records, emotions were also being shared in relation to personal stories and records of self. As summarised in Table 14, the participant was not only being affected by the storytelling and sharing process but they were able to affect the stories told and the products we created through the review process. The vignettes were able to be modified and explored for their plural meanings. These are powerful concepts and properties when considered in relation to creating records.

**Table 14 Categories of meaning: Affect**

Code and Categories	Properties
Affect	<p>The record had agency in how it is able to affect a person</p> <p>The person had agency</p> <p>People were both affected by the record-creation process and able to affect the records in their creation.</p>

<sup>406</sup> Gergen, *An Invitation to Social Construction*, 2009, 99–106.

### 5.4.2 The ritual of conversation and connecting with people

Exploring the nature of affect, feelings and emotion emphasised, that creating and supporting rituals created in the context of this research, had profound implications. In Chapter 4 I described the code of *living life in routine*. *Living life in routine* became an ongoing thread in this research which highlighted the complex nature of communicating and connecting with people.

The codes below in Table 15 were reflected in participant stories about contexts as places for connecting with others. Church was an interesting example in participant stories; it was a place of worship, a community of faith and for connecting with like-minded people who may share particular values and beliefs. The church was also contentious for Karl when he explained how he had a falling out with the church. His experience with the church was incongruous with his own values and beliefs.

**Table 15 Categories of meaning: Spiritual, values, beliefs,**

Codes and Categories	Properties
Faith	Connecting with people, place and existential
Catholic church/ community of belief	Stories of situated contexts
Importance of family	Values
Doing things perfectly/well	Beliefs
Work	Challenges to values and beliefs
Sporting clubs	
Role models	

The categories identified in this research were closely related observations and their properties not discrete. “The categories with which we as human beings apprehend the world do necessarily refer to real divisions.”<sup>407</sup> The concepts were uniquely conceptualised in the context of each participant’s own stories.

- Karl reflected a lot on family and work. Both were obviously precious to him. He was also quite pragmatic. As an accountant, he saw himself as being in a position of trust so he spoke much about setting the standard. Karl explained how he had problems with the church a long time ago and how these concerns had ruptured his relationship with the institution. It was just as important for Karl that the gardener do a good job mowing the lawn, as it was for him to be an honest and trustworthy employee managing organisational funds.
- Jean spoke many times of how family and friends had supported her after her husband had passed away. Her personal stories paid attention to how people support each other at times of need but also the importance of connecting socially. There were stories of church, outings with family and friends, and the way individuals had contributed something special to the lives of others.
- Patrick had experienced traumatic health events which had dramatically influenced his life well before the diagnosis of Alzheimer’s disease. He reflected on the good, the bad and how he was trying to make sense of these events which he could not now

<sup>407</sup> Burr, *Social Constructionism*, 2.

change. Through his experience of surgery and how he was cared for at that time, Patrick felt that it was important to make decisions now, while he could, about how he and his wife would be cared for as the Alzheimer's progressed. He also felt that people did not always understand the changes in behaviour he experienced and that it was not something he did purposefully.

Participants personal stories attested to the quality of relationships they had with other people, present, absent or lost, and the world around them (see Table 16). People spoke of how they connected and the impact of these relationships. Sometimes the implications of these relationships were described as challenging individual values and beliefs. While in participant stories, people were at times absent, present or lost so too, were things of meaning as in the records we studied or co-created absent, present or lost.

**Table 16 Categories of meaning: Relationships**

Codes and Categories	Properties
Absent Present Loss Son with needs Living close to home	Relationships to people and the environment

Quality in the collection and creation of data were also dependent on the quality of the relationships I developed with participants and their families. My approach to working with people was under scrutiny. These relationships were founded on respecting the person, their home and the people close to them. It was my responsibility to care, listen and nurture participants as they contributed to my research. Building trust and friendship meant that the roles of researcher and participant blurred. Relationships were spiritual in that they reflected the way participants connected with people and the environment.<sup>408</sup>

### 5.4.3 Physical relationships were material and social

Exploring the nature of relationships within this research was a complex arena of attempting to make explicit what may have been unspoken or was less tangible. Thus far, this chapter has been an exposition of relational statements to integrate codes and categories.<sup>409</sup> In this section I turn to exploring the notion of *human relationships* to the world around us with a focus on the person-centred record.

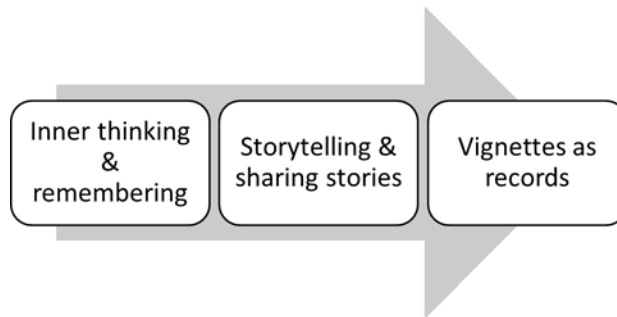
Stories of situated contexts revealed the *dimensions of human experience*. Participants related to inanimate objects or rather these objects were brought to life because of the meanings or memories given to the objects. Meanings were associated with particular people and events.

<sup>408</sup> R. Wilson, "Collective Memory, Group Minds, and the Extended Mind Thesis," *Cognitive Processing* 6, no. 4 (December 1, 2005): 227–36.

<sup>409</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015.

In this way the stories of situated contexts as connections to the physical world were both of the material worlds and socially constructed.

The category of *physical*, in its properties, was where the relationships between: inner and outer, mind and body, tacit and explicit knowledge converged. An example of this convergence of the social and material were the transitions between: inner thinking, remembering, storytelling, shared stories, and vignettes as records (see Figure 26).



**Figure 26 The process of physicalising**

The processes for co-creating records facilitated making explicit the type of thinking which is less often shared. It was the *physicalising* and bringing together personal knowledge of relationships both *material* and *social*.

**Table 17 Categories of meaning: Physical (1)**

Codes and Categories	Properties
Relationships to people, objects, places and events	Social and material relationships

This conceptualisation of physical relationships, as being both social and material, shed new light on how meaning was constructed in relation to the categories of *people*, *objects*, *places* and *events*, listed in Table 17. By theorising I began to perceive how other categories were also part of a broader human experience in which participants mutually engaged both the social and material.

As illustrated in Table 18, a single code, for example golf, could be associated with different and complementary concepts and categories. It was Karl who spoke about golf, as being of value in terms of doing physical activity. He also explained the social importance of playing and being involved in the golf club. Participating in golf as a sport and social activity was hampered by the fact that he and his wife had to share the same motorised buggy to deal with mobility issues.

**Table 18 Physical (2)**

Examples of open codes/in vivo codes	Properties
Hydro pool Alzheimer's Living with memory loss program Hobbies Golf	Activities which support connecting with people Building and sustaining relationships
Golf The kids Hydro pool Home Being looked after by the boys at school Wife - Mary Mentors	Supported by people

Table 19 includes the codes which refer to the co-creating records in this research. Co-creating records was a complex process of working to make explicit or physical those things which were not always evident in the participant's context. The participants and I were interacting with these social and material processes and objects on a number of levels.

**Table 19 Physical (3)**

Examples of open codes/in vivo codes	Properties
Reading Writing Forgetting names The vignettes on paper The life book Aesthetics – personalising the vignettes Photographs Social face to face interaction Choice – making decisions explicit	Material relationships Physicalising

The human senses were an important aspect of this category and process of *physicalising*. Participants were engaging in the acts of storytelling and reviewing of their vignettes with their whole self. They were sensing and experiencing their stories and the world around (see Table 20).

**Table 20 Sensing and experiencing**

Examples of open codes/in vivo codes	Properties
Feelings Seeing Touching Hearing	Sensing Experiencing



#### 5.4.4 Relationships: Temporality, time and place

Understanding how participants experienced relationships to others and meaningful records was deeply embedded in codes and categories associated with the continuum of time and place. The absence or presence of a person was a powerful connection which transcended time and place. It was an *embodied experience* in that participants *felt the loss* of a loved one or *missing words* as much as they recognised a *physical absence*. The categories presented earlier in Table 16 of *absent*, *present* and *Sense of loss* are augmented when considered in relationship to categories which reflect time and place (see second row in Table 21).

**Table 21 Time and the embodied experience**

Codes and Categories	Properties
Absent Present Sense of loss	Experiencing relationships through time and place
Reminiscence Presence Past Present Future Tangled threads Missing words	The human experience of time Embodied experience

It was not only people who were absent, present or experienced as a sense of loss to participants in this research. There were meaningful objects such as photos or even memories of words which had almost temporal qualities. Storytelling and co-creating records of these moments in time were techniques for realising the way human beings experience time as an embodied experience. The human experience of time is an internal experience. It was Heidegger who explained that “progress through time toward death is an internal, constitutive feature of human experience.”<sup>410</sup>

Storytelling and reviewing the vignettes were acts of making explicit and physical the experiences and stories of life which were not recorded. Memories of the past were recalled from the present. Patrick commented on the process of reviewing the vignettes;

*Patrick: It's just like clearing my head...like clearing the cobwebs away...See all this has been built up in my brain and that for so many years and just locked in there and oh well that's life. Carry on.*

The vignette review process seemed to bring into existence that which was held within the person or shared orally. I described this process of externalising stories of self to Patrick “like wearing your heart on your sleeve”.

<sup>410</sup> M. Heidegger, *Being and Time* (Oxford: Harper Collins, 2008), as cited in M. Bavidge, “Ageing and Human Nature,” in *Dementia: Mind, Meaning, and the Person*, ed. J. C. Hughes, S. J. Louw, and S. R. Sabat, International Perspectives in Philosophy and Psychiatry (Oxford: Oxford University Press, 2006), 41–53.

*Joanne: If you were to wear your heart on your sleeve, in the sense of because people don't know what's going on inside of you generally, what would be the things that you would put on your sleeve? What are the things - your heartfelt feelings about things that - or the things that are really important to you that you think, before anyone makes any judgment about you, they need to know these things?*

*Patrick: My memory is my problem, don't worry about it, I sort that out myself the best way I can. Don't worry. It'll take me time, but I'll work through it and be the answer that I want in the end.*

*Joanne: Do you generally find that that's the case? What happens when you can't?*

*Patrick: Frustration, I just have to go and ask somebody. Of course it depends how important it is too, most people say, oh don't worry, it's just a lot of bull, don't worry about it. Forget it. Used to drive me crazy, ask my father something, [he'd say] oh don't, forget it, just forget it. God, I need to know these things – just forget it.*

Patrick did not simply forget. He knew that something was absent. Like dark matter there was an energy that connected disparate events in time and place. It was his inability to maintain that thread, and the responses of others to his experiences, which caused so much frustration. Like dark energy these absences created greater distances and disconnect in his experience of self.

The participant stories and review of vignettes, provided clues to the meaning of the events recorded. Jean started working at the age of 15 after completing studies in shorthand, typing and bookkeeping at Business College. As is reflected below in this conversation with Jean, speaking about work was an obvious pleasure for Jean; it was demonstrated in the confidence with which she spoke of her knowledge of another time and place. Jean had expertise which reached beyond and transcended the here and now, and time and place.

*Jean: I was in a trustee company and the boss was a friend, his wife was a friend of my mother's [laughing] and I was petrified. If his secretary wasn't there in the lunch hour and he wanted something done and I had to go and take dictation from him. I was all right with everybody else in the office but with Mr Paterson I used to just quiver going in to him. [laughing louder]. So, I stayed there six months. And, then I...[pause] I was only probably about 15.*

*Joanne: That's so young isn't it?*

*Jean: Yes, yes...Then I got a job in an advertising firm but they also had you know they owned a laundry so we had all the book work and all this sort of thing. So I did shorthand typing and bookkeeping and then I stayed there for about three years I think it was and then I went to [name of company] and I was in the wool department there. But that was counting on an accounting machine. Yes so...It'd have totes and if you put them in the spots where you wanted it, it would add up, if it was money it would add up or take away, whatever you wanted it to do. If it was like the weights of the bails of wool that would add all those up and then you'd send the account out you know to the grazier to say, you know, this is what you know we're able to sell your wool for. [laughing positively and with a confident demeanour] I enjoyed that. I had a very happy time there.*

Jean was sharing socially and translating, what was personal knowledge from other times and places, into the present context. For Jean this was an embodied experience of people, places and events which affected her emotionally. She laughed and her demeanour became

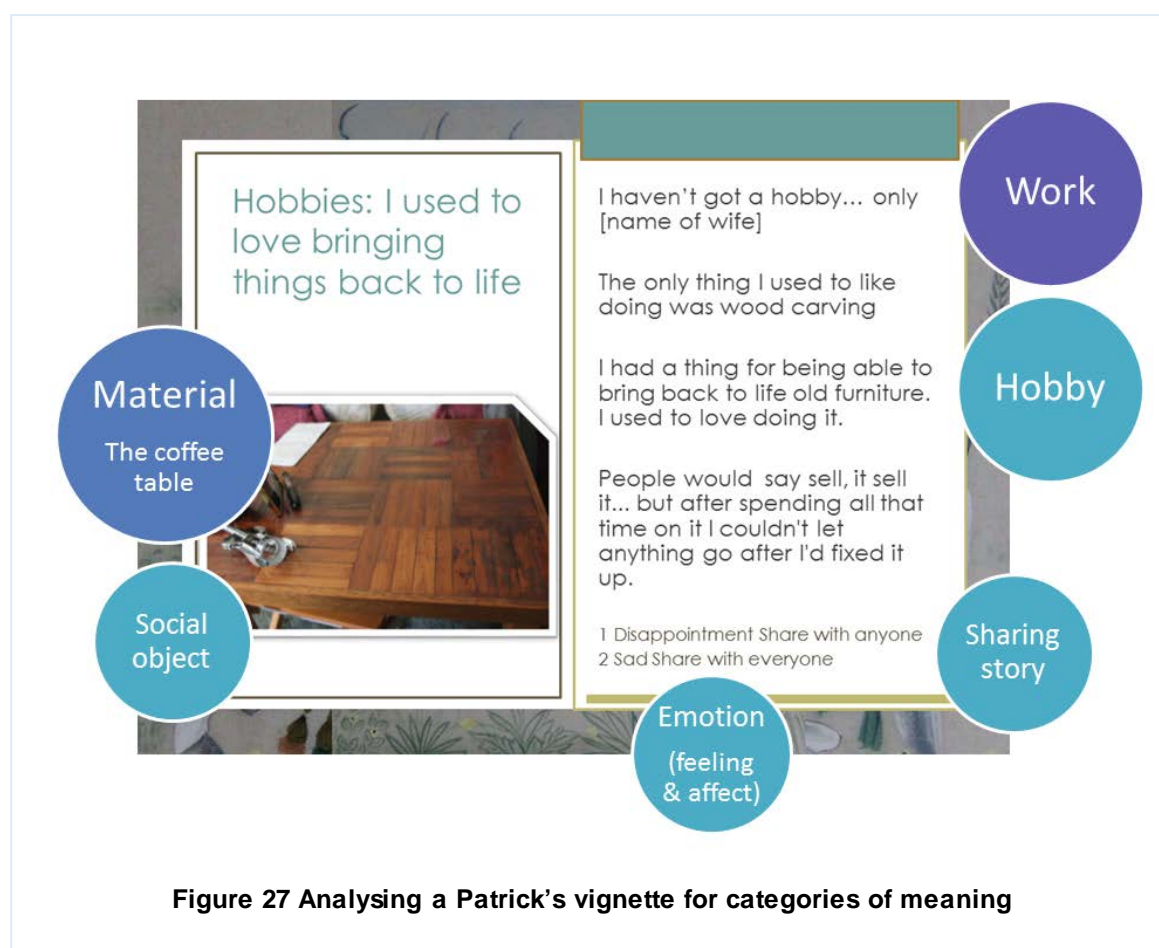
confident as she reflected on how these experiences and realised their contribution to her life overall.

In Chapter 4 Section 4.4.3, I described the findings of personal mapping with participants. Participants perceived both social and support their network through the quality of the relationships had with individuals or organisations. Through the process of analysing and coding participant stories I noticed how each person described relationships in relation to roles. They each had multiple roles not only in the present but continued to reflect on those roles and responsibilities as building blocks. The stories of work were key examples of not only what people learned but how they contributed to broader contexts. The analysis of stories revealed many codes for personal relationships, some of which are listed in Table 22. These codes were created through studying instances in the stories which reflected roles and responsibilities through which participants had learned, and which they continued to reflect upon.

**Table 22 Knowledge, learning and philosophical**

<b>Examples of open codes/in vivo codes</b>	<b>Concepts, categories &amp; analytic terms</b>	<b>Selective codes</b>
Colleagues Husband Wife Carer Profession Mother Friend Accountant Mentor Grandfather People manager Systems improver	Roles Relationships Responsibility Accountability	Knowledge Learning
Explicit Tacit Planning for the future Expressing the value of work	Personal knowledge The application of this knowledge to new contexts	Philosophical

Sharing stories and co-creating records of these stories were ways of making personal knowledge explicit. This application of personal knowledge to new contexts was an example of learning. It was particularly evident in the narratives in which participants described their concerns for the future based on past experience. The vignette in Figure 27 is an example of how a single story and vignette could be interpreted to have many meanings.



Patrick's profession and hobby were a passion he still felt even though he could not pursue it anymore due to disability. In this particular story he is describing his love of carving wood and restoring furniture. The story and Patrick's comments at the bottom right of Figure 27 reflect the emotions he expressed when he reviewed the vignettes. Patrick took great pride in the coffee table which is photographed in the image as an object that he made. The table is both a physical and a social object due to the many meanings Patrick associated with it.

#### 5.4.5 The embodied experience

Within this research reviewing and analysing vignettes was enacted socially in the context of human relationship. These encounters were composed of an embodied experience with emotions and feelings which reflected the philosophical and emotional positioning of the person. The vignettes illustrated the person's knowledge of living and learning to live in order to explain their unique perspective on the whole. These events were not limited to what the person knows of the physical world but extended to the existential; those values and beliefs that give meaning to their life to reveal what is valuable to self and beyond the self.

Analysing the vignettes revealed that through the acts of remembering the participants were not returning to the past. Rather, they were bringing the events of the past through into the present and future. Participants were telling their stories situated in their present. It was this concept of remembering in the gerund which highlighted the processual nature of making

connections between creating person-centred records and the embodied experience of those records.

Remembering was the process of revisiting people, an event or feelings of the past and reviewing this in the here and now. In this sense it was a temporal event which transcended time and brought forward a memory to a new time and place. ‘Telling personal stories’ was a category which reflected the participants situated context both now and moving into the future. As noted earlier, Table 23 reflects how the categories of absent, present and sense of loss outlined in Table 21 were augmented when considered relationship to time and place. In this sense these categories of remembering and telling personal stories were an embodied experience.

**Table 23 Remembering and telling personal stories was an embodied experience**

Open code	Properties	Selective coding
Remembering	Performing/ actively representing narratives from the past	An embodied experience
Telling/ sharing personal stories	Performing/ actively representing narratives in the present and future Making explicit	An embodied experience
Relating, through stories, to meaningful people, things and events as triggers/ records	Performing/ actively representing stories and memories of “things” as triggers for remembering	An embodied experience
Time	Temporality Human experience of time	An embodied experience
Sensing	Feeling Tacit	An embodied experience
Relationships	Relationship to social and Material	An embodied experience

I found that remembering was incredibly charged with emotion and affect. Jean had been speaking about how she met her husband, when she was taken back to the day when her husband died.

*Jean: And that was it. [There is obvious joy in remembering meeting her husband as she laughs.] He died a long time ago though [the tone of Jean's voice changes to sorrowful]*

She described where he was and his activities at the time.

*Jean: He was working over at the church stacking things up which he shouldn't have been doing you know in the queue with everybody else passed. It was before the council, they didn't collect newspapers*

*you know. If you stacked or your newspapers up you know you get money from the paper mills and that because they obviously re-made up, I don't know what they actually did it anyway he jolly well caught up on the truck and did all the heavy work and had a massive heart attack. Oh dear, I don't know. These things happen but... You've just got to accept it.*

As Jean recounted this story, her demeanour changed and I could see that she was sad. There was a powerful transition for Jean not only in the remembering but in the affective nature of the story. The affect was not delimited to the past. Jean still felt the loss and sadness though as she explained “*These things happen but... You've just got to accept it.*” It was not unusual for participants to reflect on their personal stories in a philosophical sense. Life experiences create a framework for how they made sense of the world.

The findings in this section highlighted how personal stories were a powerful way in which participants made sense of the world. The records and the inherent processes for their co-creation were the product of relationships developed between the researcher and participants. Participants were concurrently being affected by the record creation process and also affecting the creation of these records. Reviewing these records with participants generated rich data which, I as the researcher, analysed to develop categories of meaning grounded in the participant stories. These findings are significant in that they begin to explain how records were experienced by people in ways that supported their memory, identity and personhood.

## **5.5 Creating Shared Understandings and Notions of Sharing Vignettes**

Based on the learnings revealed in the previous sections of this chapter, I was very conscious of the discursive and interpersonal processes for decision-making, the participants and I were engaging in during this research. Core to these processes was the review of vignettes to explore associated and unique expressions of meaning, undertaken concurrently with the grounded theory analysis and coding. The findings of these combined analytical processes of participant data are presented under the following headings:

- Making decisions about sharing stories of self
- Shared personal knowledge and perspectives
- Reviewing vignettes and unique expressions of meaning
- Implications of recording descriptors of meaning and affect
- Co-creating records as an extension of self
- Sharing records: The concepts of secret vs sacred.

### **5.5.1 Making decisions about sharing stories of self**

With each participant I tried to explain the research process with regard to how I would use our conversations and what would I do with the data collected. I was attempting to find terms which explained these concepts with each person that I was interviewing. I was challenged to find metaphors from another context to more clearly communicate the intention of the research to participants. One of these metaphors which all three participants

understood was the notion of vignettes as part of a *memory box* or *memory bag*; based on the idea of a hospital emergency bag which an individual may have packed and ready, should they need to go into hospital unexpectedly. These concepts embodied the idea of capturing and collecting their memories and stories into something portable which could travel with the participant in times of need; something which could represent as much as possible, who the person is, their identity, their personality. Sometimes, as in the example below, it was the participant who, in seeing and reading the vignettes, created his own metaphor for the vignettes and the life book.

*Patrick: Sure, it's like an encyclopaedia.*

*Joanne: It's your encyclopaedia in fact. [I am reading the title page on Patrick's life book] "This is my story, this is about who I am, by Patrick." (Ruth reads along with the title)*

*Ruth: Woah.*

*Joanne: I've tried to use your words as much as possible. Are you able to read this? Would you like me to read it?*

*Patrick: An outline*

*Joanne: An outline of what we can do. I'll make a note on these [vignettes] to get a sense of how you feel like you could share these. So this is [reading the vignette out loud], "I have Ruth in my life, it's been..."*

Exploring and communicating concepts were activities nested in the iterative processes of the constant comparative method, data analysis and coding. It was a consultative approach to checking with participants regarding what we both understood. We were articulating the meaning, quality and significance of the stories that were shared between us. The manifestation of these activities with each of the participants was unique. With each participant there were different learnings. What worked with one person was not necessarily helpful with another.

I built on those notions of meaningful records as part of a memory bag or encyclopaedia to explore how these records we were co-creating could have a purpose and use beyond that of our immediate research context. It was in the course of beginning to review the vignettes that I asked Patrick how he might be prepared to share individual stories in the vignettes. I had developed a lot of personal knowledge about these people. I drew on the names of family and friends we had mapped in previous weeks to explore his social and support networks. In light of these networks we discussed with whom the stories might be shared. I observed some interesting qualities in Patrick's response to hearing each story; his demeanour and language modulated. Discussing the person with whom the story might be shared impacted on how he wanted to share the record.



**Figure 28 Patrick's vignette being reviewed**

The extract below is an example of the complex decision-making process that Patrick made explicit when thinking about how a vignette (Figure 28) could be shared. This excerpt includes the dialogue I had with Patrick as it reflects how the discourse was constructed as an interpersonal process, as well as an evolution of thought, affect and meaning. Patrick was responding to people present in the conversation and those absent.

*Joanne: [Speaking to Patrick] If we were to put these [vignettes] into a book, or put them on a computer, and they were made available to certain people, who would you share them with? Now we'll go into detail about this, because I don't think that's a [simple] decision, we need to go through each story for you to be able to make that decision, but that's the theme of today's session. Who would you share them [the records] with?*

*Patrick: Family [Patrick's first response].*

*Joanne: Family, who would you include in family? [Trying to understand who Patrick considered family]*

*Patrick: Um sister...[Name of sister 1], sister [Name of sister 2].*

*Joanne: Your brothers?*

*Patrick: No, no they're they're, they've got their own lives, I don't want to annoy them, they don't annoy me.*

*Joanne: Ok. (silence). Yep. And then, and then there's obviously Ruth, and then there's your kids, now I know we've discussed that.*

*Patrick: (silence) They they...couldn't give a rats.*

*Patrick: Only, only, only...this might sound a bit daft, this is (unclear), but my only concern is they'll be...(unclear)*

*Joanne: Is there anything you'd like to leave for them regardless, almost if you could leave...*

*Patrick: Well if you can put that together that'd be great.*



*Joanne: So you'd like to leave maybe the book.*

*Patrick: Yeah.*

*Joanne: Ok, anybody else in family?*

*Patrick: No, to be quite honest the rest see me as a big joke.*

*Joanne: Alright. What about friends?*

*Patrick: Uh...maybe [Name of friend 1].*

*Joanne: You've got different people, in terms of your circle of friends, you've got the church, so you've got [Name of friend 1], aunty, you've got [Name of friend 2] and [Name of friend 3]...*

*Ruth: Yeah.*

*Joanne: Would they all be in that, circle of friends?*

*Patrick: I'd say so, yeah.*

*Ruth: Yeah.*

*Joanne: Yeah? so everybody except, oh, you've got [Name of cousin 1] that's your cousin.*

*Ruth: Yeah, [Name of cousin 1] would be in it.*

*Joanne: So that's your circle of friends, I'll put as per...um...alright, and then, um...(silence) any other cousins or extended family that you can think of?*

*Patrick: At this stage they're most of them are gone.*

I was asking Patrick how he might be prepared to share individual vignettes. It is as unusual a task to think about who might have an interest in a personal story, as it is to think about which story you might like to leave for the benefit of others. Patrick's responses were complex and multiple. Patrick verbalised how he felt about his relationship with the person, to whom the vignette might be shared, as well as the content or event in the vignette. He was expressing how he was affected by the people in relationship to the story. He was considering not only what *he* might have liked but the impact of these decisions on all involved.

Patrick used a range of expressions when evaluating the vignette in Figure 28 as part of this decision-making activity. Firstly he rated the story about having his first marriage annulled. He gave this vignette a rating of ten out ten and then he categorised the story using phrases such as 'That's a happy one'. The feeling and the decision seemed to correlate. This excerpt begins with me reading the vignette to Patrick.<sup>411</sup>

*Joanne: It's been 18 years since I married Ruth; we got married at the local church, [name of church]. Is that for everyone?*

*Patrick: That's for everyone.*

*Joanne: So it doesn't matter if it's for family, or friends, or church, or residential care*

*Patrick: That's a happy one.*

*Joanne: That's a happy one. So, happy one. And that's shared with anyone?*

*Patrick: Yeah.*

*Joanne: Ok. now, it didn't print properly, so, some of them are printed on both sides and others aren't, now there aren't pictures on all of these, so if you want to find, if you want to find some pictures to help me fill them in, we can do that as well.*

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<sup>411</sup> It is important to remember how Patrick had emphasised the difficulty he experienced in reading. Reading the vignettes out loud was a way of adapting the processes to his needs.

*Ruth: Now it's coming to me.*

*Patrick: What you're trying to do.*

*Ruth: What you're trying, what you're trying to do, because you've been coming for so long now and I still, but now I sort of...*

*Joanne: You get a sense of it.*

*Ruth: Yeah.*

In this sub-section I demonstrated how it was important to create shared understandings of the vignettes as records in order to be able to discuss how they might be shared with other people.

### 5.5.2 Shared personal knowledge and perspectives

Entering into participant worlds was a discursive process. I learned about their perspectives through the stories they told and their reflection on how these impacted on their lives. In this sub-section I share experiences with Jean to illustrate the points and the process.

The following summary and reflection is from the last interview with Jean. In contrast to many of the previous interviews, where family members participated, it was just the two of us this time. It had taken time to build the relationship and the courage on my behalf to ask Jean about the personal impact of dementia. Drawing on our earlier conversations I intuited her sense of isolation and even some of the influencing factors such as transport and particularly the loss of loved ones over the years. There were themes in our conversations which highlighted patterns in thinking; not as distinct, but like a tapestry where a single coloured thread weaves its way through a range of visual or textural components of the fabric.

Jean knew she had dementia. It was something that she had not raised much in other conversations but talks about it here in this moment. The Alzheimer's disease impacted on her directly. She actively tried not to think about it but was reminded by her actions. There was a sense of the dementia lurking in the background and she explained how she would check on herself with regard to how it manifested. She compared where she was at with what happened for her mother who had dementia. Jean understood the pain the disease caused to others when the person diagnosed no longer seem to be recognised by the person diagnosed with the disease. She knew this had not happened for her – she has not forgotten any of her family or friends.

It was not only the Alzheimer's disease which has impacted so greatly on Jean. The move from her family home to be closer to her children increased her sense of loss and isolation by taking her further from friends and familiar places. It was hard making new friends as she got older so she tried to see old friends when she could but relied on others for transport. Jean felt there were decisions made without her being involved in the decision-making. One of these decisions was that of not being able to drive her car anymore. Jean made conscious decisions to do things such as cooking to maintain her independence.

Jean genuinely loves and appreciates her family. Her family love and care for Jean. Sometimes it is because we care that we do what we think the person may want or need.

Jean's account of losing the car emanates that disjunct between what she sees as necessary to support her sense of self and the way others believe she should be cared for. The accounts in this extract were told not in the company of family members. There was a strong sense of the story about Jean's car being told to me as the researcher. It was a story just between Jean and me.

Even though it was difficult to discuss with Jean the conceptual issues of how individual stories or vignettes might be shared, she was able to demonstrate through her actions to which stories she consented. This story of the car did not go into the version of Jean's life book which I delivered to her upon concluding the interviews. The life book, in its paper format, has its limitations in terms of privacy particularly when others such as family member and carers have increasingly greater control over a person's environment and belongings. If this life book were to be constructed within a technology that permitted the appropriate rights in terms of access and sharing then it would necessarily be included. It would require special rights.

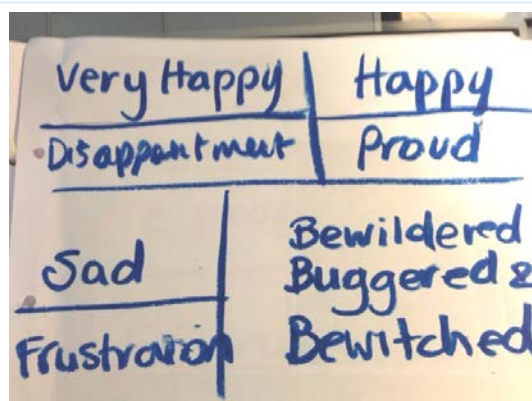
I use this writing about Jean and her family as an illustrated example of the disjunct in perspectives which a critical factor when considering person-centredness as practice. This kind of analysis is resource intensive. It relies not only on detailed study of the text but implicit and tacit knowledge of the person. It is social. It is a relationship which is modulating according to the dynamics of the situated context, event, people and time. This is a complex tapestry of stories, events and states of being. It is possible to determine the relationship between events and states of being but they are as multiple.

### 5.5.3 Reviewing vignettes and unique expressions of meaning

The representation and review of personal stories as vignettes facilitated discussions around the tacit as well as explicit meaning of the records. In sharing examples of the printed vignettes, with Patrick and Ruth, I was also able to explore how the stories could be reviewed for their unique expressions of meaning.

It was in seeing the printed vignettes as tangible objects that Patrick and Ruth began to understand the recordkeeping concepts we were exploring. Patrick was expressing decision-making based on a range of concepts and contexts. I sought to clarify what ten out of ten meant for Patrick. I introduced the idea of a *happiness scale* and we discussed what the levels of happiness would be if they were numbers from one to ten. But, defining the numbers was not that simple. As Patrick described the scale, he introduced personal nuances regarding affect and emotions. It was interesting in that we moved from numbers as a rating to the use of words. We discussed and mapped what Patrick thought his happiness scale might be.

I was initially surprised by the fact that for Patrick it was such a happy story. This raised my awareness of how the meaning of a memory or story was not always transparent. Patrick introduced his own words. I wrote these down on a piece of paper so that Patrick could read them. In Figure 29 are Patrick's words mapped to butcher's paper. It was Patrick's happiness scale and an important cognitive tool to which we could refer as we discussed the meaning of vignettes.



**Figure 29 Patrick's happiness scale**

We used the happiness scale as a way of categorising the stories and also to observe how affect might change over subsequent reviews. Below is part of the discussion regarding what categories Patrick would consider part of his happiness scale.

*Patrick: Just Sad, I'd say sad.*

*Joanne: Sad. And anything worse than that?*

*Patrick: Bewildered...*

*Joanne: mmm*

*Patrick: That's one of me old man's sayings, bewildered bugged and bewitched.*

*Joanne: And what does that mean for you?*

*Patrick: Haven't got a clue, don't know what's going on, but there'll be an answer somewhere.*

*Joanne: So do we need extremely happy or just very happy?*

*Patrick: Very happy.*

*Joanne: So we've got very happy, happy, sad, and we've got bewildered bugged and bewitched.*

*Patrick: Yeah.*

*Joanne: Can you read that, just a little bit?*

*Patrick: Yeah, oh yeah. The trouble is the size of the letters and they all run into each other.*

*Joanne: Ok, so if I do it differently. If I use a bigger pen does that help?*

*Patrick: Yeah, yeah.*

*Joanne: So if we put...very happy...happy...sad...(pen noises) how's that?*

*Patrick: spot on.*

*Joanne: better? Ok, Alright. So this one about the annulment, where does that sit on the scale?*

Patrick was able to point to the term which depicted where the story sat for him on his happiness scale. We discussed with whom Patrick might or might not want to share this story. These decisions were contextual in that they represented how he felt in that moment.

*Joanne: Happy? And who would you be happy to share that with? Remember we were talking about family?*

*Patrick: Family,*

*Joanne: Friends?*

*Patrick: Family, friends, yep.*

*Joanne: Yeah, and what about people who might need to care, to look after you but don't know?*

*Patrick: Yeah, that's good, that's yeah that gives them a bit of an insight [into his life]*

*Joanne: So you're happy for anyone to look at this?*

*Patrick: Yeah*

*Joanne: Pretty much anyone could have a look at this?*

*Patrick: Of course*

*Joanne: Is there anyone you wouldn't want to have a look at this? (silence)*

*Patrick: At this stage no.*

The review of the same vignette in two separate interviews revealed how a person can feel about and experience their own personal story differently.

- **Review 1:** Happy. Share with some people. Share with anyone.
- **Review 2:** Very, very happy. Share with everyone.

The terms chosen are deceptively simple in light of these conversations we had regarding the affective nature of the record and who the record could be shared with. I undertook the same review of affective meaning with Karl. As I worked through the vignettes I annotated each story with the words he used to define how he felt. I asked how he would be prepared to share these stories and with whom (see Figure 30 and review notes below).



**Figure 30 Reviewing a vignette with Karl**

- **Review 1:** Feelings: Love, somewhere in between proud and happy. Proud that we did make the decision. A lot of people said we could have waited a year or two but we made the decision. Share with anyone.

- **Review 2:** Part of life. Lucky to get someone so great. It was a big decision/love/proud & happy. Share with anyone.

Reviewing vignettes and making explicit the unique expressions of meaning were central to developing the person-centred record. I learned through this experience that the effectiveness of the techniques for reviewing vignettes was dependent on a number of factors. These include the following points:

1. How the participant was feeling on the day impacted on their attention span and ability to communication.
2. The participant was fresher at the start of the interview so reviewing the first vignettes was always more effective. The remaining vignettes were the first to be reviewed in the next interview.
3. Each participant's ability to deal with abstract concepts varied. These review processes were possible with Patrick and Karl. Patrick especially was very articulate and would contribute his own ways of conceptualising the vignettes we were creating. I struggled to undertake this level of review with Jean whose attention was more difficult to maintain. Though, over the weeks of interviews with different family members in attendance, I observed how she effectively negotiated conversations with people and pets. The descriptive words may not have always been explicit in the context of an abstract discussion but the storytelling was intentional and directed to another individual.
4. Exploring the range of words that described the ways each person could feel was helpful. I could explore with the participants their own vocabulary for how they felt and how they ascribed meaning. I was also learning how each person expressed themselves.

#### 5.5.4 Implications of recording descriptors of meaning and affect

As described in Section 5.4.1, the literature on feelings and affect revealed that they are important descriptors for meaning.<sup>412</sup> There were potential problems with recording descriptors of affect. The way feelings and affect are described varies depending on who is purporting the knowledge. What became clear through this research is that affect and the way we feel about things is both relational and contextual. What could be recorded and what are the implications for those actions?

The identification and stabilising of persistent affective patterns in a social or personal formation can require a lot of retrospective constructive work. But this work is also constitutive of the phenomena it describes and inevitably over-simplifying. When a psychotherapist, for instance, traces out the affective repetitions in an individual life, or when a sociologist or historian traces out the structures of feeling for a generation or community, they risk constituting and solidifying the practice as they describe it. The narrative of affect

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<sup>412</sup> M. Wetherell, *Affect and Emotion: A New Social Science Understanding* (London: SAGE Publications, 2012). Kindle Edition.

emerging from the reconstructive work becomes itself a template and guide for organising future practice. It creates (and can institutionalise) what it tries to describe.<sup>413</sup>

Recording descriptors of feeling or affect risked institutionalising what was being described. In this research, emotions, feelings and affect were not simple categories or events. They were in fact key processes of encounter. Each story and its telling was unique for each person. The details of the story may have been consistent across each telling or review but the impact or affect showed potential to shift and it did.

According to Harré, the identification of emotions requires taking “into account how a person is appraising an object or situation.” It is the person who knows the circumstances or events which validate why they feel a particular way.<sup>414</sup> Affect is a part of a complex process where “‘emotional states exist’, and are manifested through bodily process, overt expression and subjective feeling.”<sup>415</sup>

Affect is an embodied experience. Affect is not fixed; its manifestation may be subtle or more overt. Though participants may have described affect or emotions within the context of telling their story, this was not the full extent of how the person was affected or was able to affect the story. The stories behaved like dark matter to evidence what may not be said. For each person in this research, emotions, emotional states, subjective feelings and affect were unique. This finding raised important questions regarding the implications of recording the embodied experience or meaning which are ever evolving.

I would like to recapitulate the process of reviewing vignettes. The storytelling and conversations became the process for capturing stories as vignettes. These vignettes metamorphosed into a co-created personal record, and a product, which had the potential to reflect stories of self. The tangibility of the product facilitated the exploration of the story as well as the record. The process could be explored to understand affect for the person as well as how the person might be able to affect the record. The personal record could through this process be a process for knowing what is person-centred and hence support personhood.

The codes in Table 24 focused on the production, decision-making and construction of records within this research. Telling personal stories and co-creating records were performative acts.

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<sup>413</sup> Ibid., Kindle Locations 2538–2543.

<sup>414</sup> R. Harré, ed., “Affect and Social Context: Emotion Definition as a Social Task,” in *The Social Construction of Emotions* (Oxford: Basil Blackwell, 1986), 3.

<sup>415</sup> T. R. Sarbin, “Emotion and Act: Roles and Rhetoric,” in *The Social Construction of Emotions*, ed. R. Harré (Oxford: Basil Blackwell, 1986), 87.

**Table 24 Extension of self (1)**

Examples of open codes/in vivo codes	Properties	Selective codes
Memories Stories Meaningful objects Relationships	Representing Performing Making new memories Shared memory-making Physicalising/recording	Extension of self
Conceptualising the Life Book Conceptualising the personal archive Ownership Affordances of paper in this context Aesthetics Meaning Research product Personal use Able to be added to or changed	Agency: affecting and being affected	Affect Extension of self
Everyone Anyone Share with anyone except the gardener Share with anyone Eat your heart out Bore others to tears	Categories for sharing the stories Making decisions	Extension of self

Recording descriptors of meaning and affect have particular implications in this context of co-creating records. In this sub-section I have identified some key factors which influence the way we understand and record meaning and affect. Creating records is a process for making explicit these embodied experiences but raises concerns in the recording of when affective characteristic is shifting and changing. Working with affect requires a sensitivity to the embodied experience and the record as an extension of self.

### 5.5.5 Co-creating records an extension of self

Co-creating person-centred records was a process for physicalising knowledge of self and created the more abstract code of 'extension of self' (see Table 25). In light of each participant's cognitive changes and its impact on communication, co-creating person-centred records served the purpose of making explicit a person's thinking as well as their experience.

Patrick had in the first weeks of our conversations begun to review his own experiences of illness and the impact on all areas of his life. In light of this experience, where he felt a loss of control, Patrick expressed the desire to plan and make decisions for the future. These stories became tangible through their telling and the creation of vignettes which we could review and discuss. I would not describe these records as a proxy for the person. Rather these multiple versions of records were techniques and tools for facilitating discussion and interpersonal



relationships. The purpose of the communication was to stay connected to the individual as they evolve and change.

**Table 25 Extension of self (2)**

Open code	Properties	Selective coding
Sharing the stories/ vignettes	Physicalising Making explicit Making connections: material and social	Extension of self
Sensing	Tacit Feeling/ emotion Senses	Extension of self

The vignettes as records became a way of representing self. Over the extensive period of in-depth interviews participants continued to share certain stories, which I described in Chapter 4 as a constant. Each person was also learning and adapting to their physical and social worlds. The interview excerpt below was an example of what I describe as reconciling personal experiences. Karl and I were reviewing one of the vignettes of his experience at school.

*Joanne: So when you read this story, what sort of feeling or emotion do you associate with that?*

*Karl: Well it reminds me of what I know, but I think it would be better for people to understand what happened when I was growing up. Like perhaps the kids might realise it was a completely different era, compared to what they've got now.*

*Joanne: And why is it important to you?*

*Karl: Oh I just think I turned out a much stronger person, able to make decisions, and I was making them [decisions] younger. Because I was the one that, because my mother encouraged me to look after the money, the [name of association], anybody I've been in, I'm always running it, well money side, because the others don't want to do it.*

Physicalising tacit knowledge through co-creating records helped make explicit how a person felt about their experiences and their stories of self. The process of reviewing these stories created opportunities for participants to review both the story and how they felt about the story.

### **5.5.6 Sharing records: The concepts of secret vs sacred**

Reviewing the life book with participants highlighted for me, that the way people felt about their stories recorded as an extension of self and in their situated context, influenced their decisions regarding how the person-centred records could be shared. It was the final review of the life book with Patrick which distinguished for me the subtle difference which existed between identifying records as secret or sacred.

Throughout the interview process, Patrick was able to discuss quite clearly the emotional impact of each story in a vignette. He made explicit a range of emotions or affect he associated with the meaning of each record. We explored the people with whom he might be prepared to share each individual vignette. This review process was undertaken over weeks 4 and 5. In response to Patrick's feedback I created what we called a sealed section in his life book, which would only be accessed by others such as carers under very specific circumstances. These were separated out not so that Patrick could not access them but because they were records of a sensitive nature. He did not want others to be offended by these stories which reflected conflicting values and beliefs. They were sacred in that they presented those existential events that powerfully influenced Patrick.

These stories had the potential to change the way others would perceive Patrick and this in turn could change the way he felt about himself. It was in the last interview, when I presented him with two parts to the life book – one of which was in a separate and sealed folder, that he changed his mind about how the sealed records could be shared. In concluding this process he did not feel the need to keep them separate anymore and that these are all a part of who he is.

Jean had also confided in me regarding decisions which were made outside of her control by her daughter and doctor regarding her ability to drive. She did not explain how she felt about this to her family because she didn't want to upset anyone. She appreciated their care and concern. This story did not become a part of the life book I left with Jean but it is a salient vignette in researching person-centred records. These records would with the more rigorous controls, rights and permissions contribute to understanding Jean's view on her world. Karl was adamant, when discussing how to manage sensitive stories with others, that others already knew these stories so they were not secrets which needed to be protected.

The choices we make with regard to sharing personal stories are made in relation to how we are affected by them. It is in ways easier to understand how we might have been affected in the past or present. How we might be affected in the future is more difficult to ascertain. The future is dependent on situated contexts and that it is harder to imagine, yet alone control. Contexts as they are becoming are filled with unknowns. For the person with Alzheimer's disease, change in contexts is more dramatic due to the rate of change in self and how others relate to self.

Constructivist inquiry starts with the experience and asks how members construct it. To the best of their ability, constructivists enter the phenomenon, gain multiple views of it, and locate it in its web of connections and constraints. Constructivists acknowledge that their interpretation of the studied phenomenon is itself a construction. [These assumptions are enacted in constructivist grounded theory through] the production, quality, and use of data, research relationships, the research situation, and the subjectivity and social locations of the researcher.<sup>416</sup>

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<sup>416</sup> Charmaz, *Constructing Grounded Theory*, 342.

I was not there to judge or validate truth or fact. I was focusing on the person's experience as their truth with the understanding that what is believed to be real is also true in its consequences.<sup>417</sup> Thomas Theorem states that "if situations are defined as real, they are real in their consequences".<sup>418</sup> There was no right or wrong way to manage access to these person-centred records. It was important to understand the changing needs of the person in diverse contexts, and the possible repercussions of interpreting and using personal records. There were stories which were sacred and needed to be treated with respect of the person and to the record. There were records which were secret due to how people felt the stories would impact on themselves and others. Creating shared understandings of the records the participants and I were co-creating was a key feature of the decision-making process in this research.

## 5.6 Conclusion

In this chapter I revealed the codes, categories and theorising that were achieved through the analysis of empirical data collected in this research and I discussed their properties in relation to how those codes were interpreted. The process addressed the aim of this research and the research questions. The aim was to explore how personal recordkeeping could be used to support memory and identity for the person with early stage dementia. Further, to explore how second generation grounded theorising contributes to archival theory and possible implications for practice. Questions asked in this exploration included:

- How do individuals perceive what is important in creating their own personal records in their current context of early stage dementia?
- How do people represent their own memories and stories in ways that support the integrity of their identity and memory?
- How is meaning supported and sustained in the process of co-creating records?
- How do we achieve a rich understanding of the ethical issues and processes involved in this kind of record co-creation?

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<sup>417</sup> W. I. Thomas and D. Swain Thomas, *The Child in America: Behavior Problems and Programs* (New York: Knopf, 1928), [https://books.google.com.au/books?id=yNALAwAAQBAJ&dq=the+child+in+america:+behavior+problems&source=gbs\\_navlinks\\_s](https://books.google.com.au/books?id=yNALAwAAQBAJ&dq=the+child+in+america:+behavior+problems&source=gbs_navlinks_s).

<sup>418</sup> Bruce G. Link et al., "Real in Their Consequences: A Sociological Approach to Understanding the Association between Psychotic Symptoms and Violence," *American Sociological Review* 64, no. 2 (April 1, 1999): 316, doi:10.2307/2657535; Thomas and Swain Thomas, *The Child in America: Behavior Problems and Programs*.

The detailed analysis of those meaningful stories, and the vignettes created from those stories, was a way of deconstructing complex narratives into their constituent parts. This process did not simplify the narrative content but rather illuminated the many layers of meaning embedded in the participant voices and their stories as they were shared and recorded. Key findings of this level of analysis included new insight into:

- The complex nature of the human relationship to records as they were socially constructed. Record creation was the product of human interaction; it was an interpersonal activity which supported sharing and recording meaningful stories situated in particular contexts.
- Deeper understanding of how storytelling and co-creating records reflected memory, identity and meaning.
- How participants made decisions regarding how personal stories might be shared.

Co-creating person-centred records and supporting personhood were theoretical and methodological positions that I subscribed to. This position is founded on literature and discourses which reinforced my belief that an individual's experience is unique and contextual. The findings in this chapter are constructed from the data generated with participants and through their unique experiences. The analysis of this grounded data revealed salient dimensions in the human processes which began to explain how storytelling and co-creating person-centred records were both an embodied experience and an extension of self. These stories and person-centred records were social and material products; they represented individual's perspectives of self and in the world. These records reflected the ways people engaged and connected with others, their values and beliefs, their knowledge and learning, and how this influenced their philosophical position. While records had agency in that they were able to affect the person, co-creating person-centred records were acts of agency in that participants were able to represent and affect their own stories of life and self.

## 6 Findings 3: A Social Constructionist Grounded Theory of the Person-Centred Record

### 6.1 Introduction

This is the third chapter in which I present the findings of this grounded theory study. Its purpose is to demonstrate how the theory was conceptualised and constructed in this second generation grounded theory research in order to explain “the phenomena that is the focus of the research”.<sup>419</sup> Theory is “an explanatory scheme comprising a set of concepts related to each other through logical patterns of connectivity.”<sup>420</sup> Within second generation grounded theory and the implementation of a social constructionist lens, theorising emphasises the researcher’s practice for understanding and explaining relationships within phenomena which are highly contextualised.<sup>421</sup> The way in which relationships between concepts are defined and described is, according to Charmaz, dependent on the philosophical influences within the research.<sup>422</sup> The findings from the analysis and coding as detailed in Chapters 4 and 5 were the basis for the development of an integrated grounded theory. To integrate is to bring together two or more things or characteristics to form a whole.<sup>423</sup>

In this chapter I present The Experiential Model of the Person-Centred Record as a grounded theory. Initially, I present the theory and then throughout the chapter, I explain the concepts that are embedded in the theory. This chapter is organised under the following sections:

- Section 6.2: Experiential Model of the Person-Centred Record is presented.
- Section 6.3: The model and the embedded concepts are discussed.
- Section 6.4: Theory of the Experiential Model of the Person-Centred Record

### 6.2 The Experiential Model of the Person-Centred Record

In this section I introduce the Experiential Model of the Person-Centred Record. The model and the underpinning concepts are product of grounded theorising. The findings presented in Chapters 4 and 5 form the background and basis for the model. The model is a major finding in this research. As it is derived from the grounded theory process, the model is conceptual and the schema that I used to illustrate these concepts emerged from the data and findings.

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<sup>419</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015, 109.

<sup>420</sup> Ibid., 108.

<sup>421</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 128.

<sup>422</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*.

<sup>423</sup> “Integrate: Definition of Integrate,” *Oxford Dictionary*, accessed October 14, 2015, [http://www.oxforddictionaries.com/us/definition/american\\_english/integrate](http://www.oxforddictionaries.com/us/definition/american_english/integrate).

The way the concepts are positioned in the model is not causally related but rather a logical association as iterated in the grounded theory storyline. The concepts are types of knowledge or knowing which could be identified and explored in the context of personal storytelling and co-creating records which are person-centred. The Experiential Model of the Person-Centred Record represents ways of framing and reframing perspectives. It provides ways of looking for and challenging underlying assumptions, listening in the gaps, the silence, the various ways perspectives are voiced.

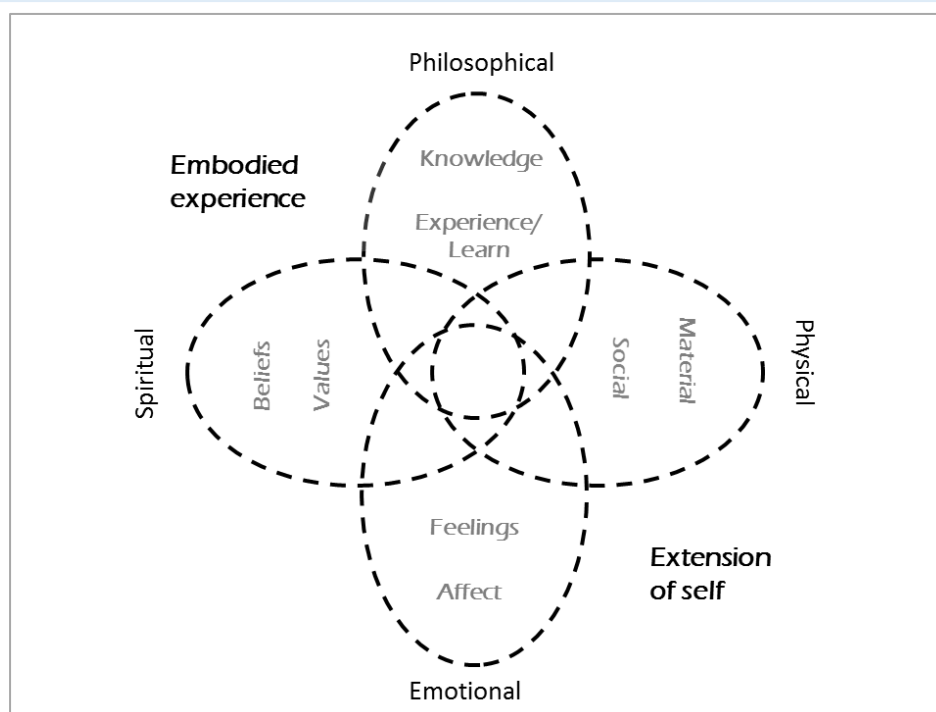
Interpreting this model requires an empathetic as well as analytic approach. It is not a model for predicting the nature of a person's responses to events past, present or future. It can, however, position the users closer to an interpretation of the personal experience. The concepts spiritual, philosophical, physical and emotional are high level abstractions of what was explored through practice and findings. These categories of meaning encompass the presence and patterns of embodiment in relationship to the process of co-creating records as an extension of self. This evidencing of self may be interpreted in many ways or adapted to new contexts. These concepts are not definitive but part of an interpretive process of referencing that which is observed and learned in relation to people and their person-centred records.

While personhood was in this research a philosophical approach to working with people and their data, person-centredness was how that approach played out in practice and influenced the records co-created. Person-centredness in this study meant that the person and their perspective was the focus of the records.

Theoretical coding allowed me to construct the model; by exploring the relationships between codes and how they integrate into a theory of the Experiential Model of the Person-Centred Record.<sup>424</sup> In Figure 31 I have drawn a schematic representation of the Experiential Model of the Person-Centred Record.

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<sup>424</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015, 118–122.



**Figure 31 Experiential Model of the Person-Centred Record (Schema)**

The model identifies key dimensions explored through the co-creation of person-centred records. These dimensions explicate the experience of making explicit personal memories and stories as an extension of self and as an embodied experience. The storytelling and the creation of vignettes were both social and material. These person-centred records reflected individual knowledge and learning which underpinned their philosophical approach to life and others. The records and their processes for co-creation had emotional properties. Participants experienced feelings in relation to these processes; they were both affected by and able to affect the records. The spiritual is of particular significance; it is the way people connect with themselves, others and the world through representations of values and beliefs.

The dimensions in the model were the product of theorising the codes and categories which are discussed in Section 3 of this chapter. The model is a representation of concepts which highlight the characteristics of person-centred records generated through this research. Markman explains that a conceptual representation is a way of organising categories and information into related groups. These representations lack movement between concepts. They are a technique for capturing the essence of the subject at hand.<sup>425</sup>

The concepts in the Experiential Model of the Person-Centred Record are not entities in themselves. I describe them as indexical in that they are concepts which are defined by the context or object to which the term refers.<sup>426</sup> This reference is not fixed. Rather it points to

<sup>425</sup> A. B. Markman, "Conceptual Representations in Psychology," in *Encyclopedia of Cognitive Science* (John Wiley & Sons, 2006), <http://onlinelibrary.wiley.com/doi/10.1002/0470018860.s00501/abstract>.

<sup>426</sup> D. Braun, "Indexicals," in *Stanford Encyclopedia of Philosophy*, ed. E. N. Zalta, 2015, <http://plato.stanford.edu/entries/indexicals/>.

the uniqueness of meaning within a person's experience which is also social, contextual and temporal. The indexical may mean different things in relation to these unique context.<sup>427</sup>

Categories of meaning were signifiers. The concepts in the model do not in themselves make explicit the meaning, but rather point to that which was meaningful in the telling of personal stories and the process of co-creating personal records. It was the characteristics of co-creating the record, as a process, which enabled the record to be congruent with the person and therefore be person-centred. In the rest of this section I present a brief overview of the schema and the embedded concepts.

### 6.2.1 An embodied experience

Working with and understanding the embodied experience was central to co-creating and understanding person-centred records. All the dimensions represented in the schema that is, philosophical, spiritual, emotional and physical were known through the embodied experiences of the participants.

Sharing stories and co-creating person-centred records were not bound to the resources of words and text alone. They were also embodied experiences in which participants in the storytelling event were “physically present to each other...as communicative resources because bodies are visible ‘objects’ to which it is possible to ascribe meaning.”<sup>428</sup> “Being an embodied agent itself involves being embedded in the world and links the inner self with the outer self. Indeed, being embodied – because of the way our bodies reflect our selves and also participate in the world – breaks down the distinction between the inner and outer.”<sup>429</sup>

### 6.2.2 An extension of self

Telling personal stories and co-creating records were processes for making explicit and externalising these records as an extension of self. This concept of creating an extension of self through records is an act of agency implicit and associated with identity and memory. The dimensions represented in the schema that is, philosophical, spiritual, emotional and physical were part of what was experienced of person-centred records as an extension of self.

The dimension *extension of self* refers to human agency as the capacity to not only know the world internally [embodied] but meaning as it is manifested into what Merleau-Ponty describes as “observable actions.”<sup>430</sup> The use of visual aids facilitates communicating with people with

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<sup>427</sup> Indexicals are keenly discussed and debated in philosophy; in relation to “theory of meaning...the logic of arguments...the nature of belief, self-knowledge, first-person perspective, and consciousness.”Ibid.

<sup>428</sup> C. Goodwin, “Action and Embodiment within Situated Human Interaction,” *Journal of Pragmatics* 32, no. 10 (September 2000): 1489–1522, doi:10.1016/S0378-2166(99)00096-X; A. Kendon, *Conducting Interaction: Patterns of Behavior in Focused Encounters* (Cambridge: Cambridge University Press, 1990), <https://books.google.com.au/books?id=7-8zAAAAIAAJ>, as cited in L.-C. Hydén, “Storytelling in Dementia: Embodiment as a Resource,” *Dementia* 12, no. 3 (May 1, 2013): 360, doi:10.1177/1471301213476290.

<sup>429</sup> J. C. Hughes, “The Situated-Embodied-Agent,” in *Focus on Alzheimer's Disease Research*, ed. E. M. Welsh (New York: Nova Biomedical Books, 2003), 254.

<sup>430</sup> E. Matthews, *The Philosophy of Merleau-Ponty* (London: Taylor & Francis, 2014).



dementia.<sup>431</sup> Co-creating person-centred records was a process for extending the communicative resources and ascribing meaning. It provided supported activities for capturing those stable stories of what Bamberg describes as the ‘gist’ of the story while allowing for the person to iterate and adapt the stories and meaning to the situated audience.<sup>432</sup> This shared process of inscribing the stories of self creates the record as an extension of self. The activity highlights the social nature of co-creating personal records as intentioned storytelling events and subjective constructions. Storytelling between married couples has been described in research as a way of filling in the gaps or shared remembering.<sup>433</sup> These concepts are congruent with the notion in social constructionism of distributed cognitions where “rational activity does not reside alone in the individual head but may be distributed across an array of persons and objects.”<sup>434</sup>

### 6.2.3 Physical, material and social

Physicalising or making explicit personal knowledge is both social and material. In the Experiential Model of the Person-Centred Record, the physical dimension highlights the way records are socially constructed. Records are these activities and the manifestation of these as products. The physical dimension was composed of people, social interactions and the material environment which already in the lives of participants.

Though the physical and material context in social constructionism is limited in how it is addressed, Gergen acknowledges the inextricable relationship between social relationships and the material contexts in the “environment that sustains our lives”. He maintains that dealing with the material world as a social construction is a major challenge and deserving of further work.<sup>435</sup> Person-centred records were part of the interactional environment which influenced how personhood was constructed and lived. Material and social aspects of life include the use of physical space, engaging in activities and interacting with others.<sup>436</sup>

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<sup>431</sup> A. Mason and H. Wilkinson, “Don’t Leave Me Hanging on the Phone: Interviews with People with Dementia Using the Telephone,” in *The Perspectives of People with Dementia: Research Methods and Motivations*, ed. H. Wilkinson (London: Jessica Kingsley Publishers, 2002), 194.

<sup>432</sup> M. Bamberg, “Twice-Told-Tales: Small Story Analysis and the Process of Identity Formation,” in *Meaning in Action: Constructions, Narratives, and Representations*, ed. T. Sugiman et al. (Tokyo: Springer Japan, 2008), 38, [http://dx.doi.org/10.1007/978-4-431-74680-5\\_11](http://dx.doi.org/10.1007/978-4-431-74680-5_11).

<sup>433</sup> Hydén, “Storytelling in Dementia: Embodiment as a Resource.”

<sup>434</sup> K. J. Gergen, *Relational Being: Beyond Self and Community* (Oxford: Oxford University Press, 2011), 380.

<sup>435</sup> D. Nightingale and J. Cromby, *Social Constructionist Psychology: A Critical Analysis of Theory and Practice* (Buckingham: Open University Press, 1999), 99; Gergen, *An Invitation to Social Construction*, 2009, 54.

<sup>436</sup> “personhood is constructed through one’s world, a focus on the living environment becomes critically important for conceptualizing and understanding personhood...The interactional environment, retains this focus on the importance of one’s interactions with others, but extends it to recognise that personal relationships are only one aspect of the immediate environment within which the person with dementia interacts on a day-to-day basis. Other aspects such the use of physical space and engagement in activities also provide interactional opportunities which can either foster or erode one’s sense of personal competence and uniqueness, and hence personhood.” D. O’Connor and B. Purves, eds., *Decision-Making, Personhood and Dementia: Exploring the Interface* (London: Jessica Kingsley Publishers, 2009), 127–128.

### 6.2.4 Spiritual, beliefs and values

The spiritual dimension of the model is about how the person connects and engages with themselves and the world around them. It incorporates the expression of beliefs and values through intrapersonal and interpersonal interactions.

The findings in relation to the interpersonal processes and the co-creation of rituals in this research were compatible with Wilson's description of the spiritual, in which he describes how connections are made with people. Spirituality is integral to "healthy living for all people" along with "mental, emotional and physical health".<sup>437</sup> "Relationships do not merely shape reality, they *are* reality".<sup>438</sup> Relationships are described by Gergen as being essential in affirming an individual's feelings and life stories.<sup>439</sup> The spiritual, as characterised in this research, is the affirmation of the person's experience, their feelings and stories, and their inherent values and beliefs.

### 6.2.5 Emotional, affect and feelings

The dimension of emotion which incorporates, affect and feelings is pivotal to the how person-centred records were experienced, understood and represented. People experienced emotion, affect and feeling uniquely and in relation to the records being co-created. The expression of these experiences was emotionally nuanced.

The person was affected through relationships with self and others, and through the co-creation and review of person-centred records. They used language and physicality to express meaning. The words we use to express meaning such as love, anger, hope etc. are "typically embedded within full-blown performances – including gestures, gaze, and posture...It's not that we have emotions, a thought or a memory as much as we do them."<sup>440</sup> These performances, these expressions of meaning are always in relationship to someone, whether implicitly or explicitly. Emotions are shared. "This is embodied action, and such action has meaning only within and because of relationship."<sup>441</sup> The emotional in this research affirms peoples' embodied and situated selves by acknowledging their feelings and their capacities to affect and be affected.

### 6.2.6 Philosophical, knowledge and experience/learning

The philosophical dimension of the model was influenced by the person's intuitive knowledge, their ongoing experiences and learning. This dimension is how people positioned themselves philosophically in the world and in relation to their identities and others.

Meaning was expressed through different ways of knowing. Knowing and learning were highly nuanced within personal stories and person-centred records. Knowing was a tacit and

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<sup>437</sup> Wilson, *Research Is Ceremony*, 89.

<sup>438</sup> *Ibid.*, 7.

<sup>439</sup> Gergen, *An Invitation to Social Construction*, 1999.

<sup>440</sup> Gergen, *An Invitation to Social Construction*, 2009, 99.

<sup>441</sup> *Ibid.*, 100 and 106.

embodied experience. Knowing was a recognition of self in stories and the records co-created. The embodied experience was a bridge which challenged the philosophical boundaries of mind versus body. Human learning is a “combination of processes whereby whole persons construct experiences of situations and transform them into knowledge, skills, attitudes, beliefs, values, emotions and the senses, and integrate the outcomes into their own biographies.”<sup>442</sup> The philosophical, as characterised in this research carried the authority of the person’s knowledge, life understandings and learning.

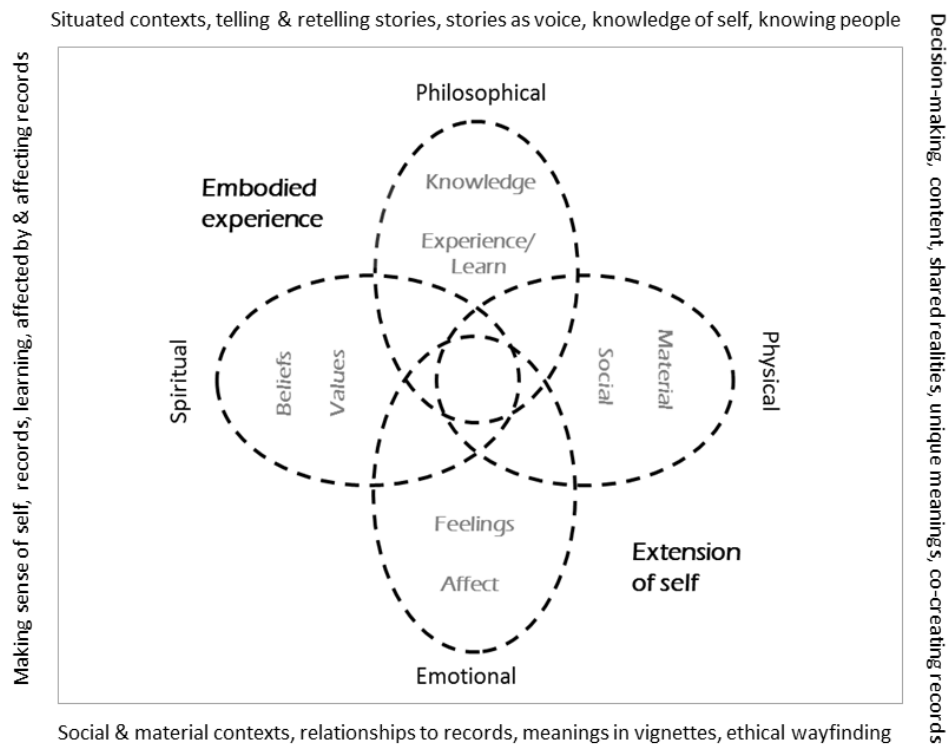
In conclusion, the Experiential Model of the Person-Centred Record was generated through second generation grounded theory research. It was grounded theorising which brought concepts together in a unique way and with nuanced relationships. These findings elucidate salient dimensions of the human experience of records grounded in the data and affirmed in the literature. People in this research were told their stories and represented them through co-created person-centred records. There were many meanings and rather than being fixed, we used processes which reflected many ways in which human beings experience the world: physical, emotional, philosophical and spiritual.

### **6.3 *Relating the Findings to the Concepts in the Theory***

In the previous section, the grounded theory of the Experiential Model of the Person-Centred Record was presented. In this section, I relate the findings of the research to the concepts in the theory. The findings reported in the previous chapters are consolidated and presented summatively eight sub-sections. Figure 32 highlights key words associated with these findings and shows them surrounding the diagram of the model. In keeping with the postmodern tenets of this research, the examples from which the words emerge are dynamic and interactive. These key words reflect the concepts that shaped and informed the grounded theory, and hypothetically in the future they may provide examples to guide the use of the grounded theory.

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<sup>442</sup> P. Jarvis, *Adult Education and Lifelong Learning: Theory and Practice*, 4th ed. (Abingdon, Oxon: Routledge, 2010), 111.



**Figure 32 The Experiential Model of the Person-Centred Record  
Surrounded by Findings**

The sub-sections are as follows:

- Living in a situated context
- Stories as voice and knowledge of self
- The situated context was social and material
- Extensions of self through relationships with records
- The meanings within the person-centred record
- Making sense of themselves in the world
- Being affected and affecting records
- People making decisions about the 'rightness' of the record.

### 6.3.1 Living in a situated context

A significant influence in the Experiential Model of Person-Centred Record is the person's situated context. Throughout the previous results chapters (Chapters 4 and 5), the need for the archivist as researcher to work with and to understand people in their situated contexts was fundamental. The person-centred record is about the people for whom these records have particular purpose and meaning.

The personal experience is the situated context. What people feel and know about their situations and situatedness is the internalisation of their embodied experience. We are creating records which represent the peoples' views of their situated contexts.

It was important to acknowledge that the spiritual is a way of working with people in connection to others and the world beyond. The spiritual is underpinned by the person's core values and beliefs. It is when these values and beliefs are misrepresented that there is a perceived disjuncture in how the record connects with and represents the person and the world around them.

Emotional experience, which includes affect and feelings, is generated within the situated context. Much of this is tacit. So, it is essential that the practices of the archival researcher consider and attend to the nuanced emotional aspects of the person with whom the person-centred records are being co-created. Similar sensitivities apply with regard to the person's experience, knowledge and learning. The influence of the person's philosophical approach to life and the co-constitution of person-centred records related to their humanness requires authentic respect and attentiveness.

The way people in their situated contexts experience the world has multiple facets. It is at once internal, external, social and material while being spiritual, emotional, physical and philosophical. People in their situated contexts are at once embodied and evolving extensions of self in their past, present and future worlds. For the archival researcher awareness and sensitivity to these dimensions are core to practice and co-creating person-centred records.

### **6.3.2 Stories as voice and knowledge of self**

The results of this research reveal that the researcher as archivist needs to attend to and understand participants' stories as voice and as expressions of self. This was demonstrated in the research in multiple ways. The findings challenged some common assumptions associated with people with dementia. The person with dementia is often associated with forgetting but these people were learning and trying to remember. These stories as personal records were the person's voice; they told their own stories as personal records through a continuum present, absent, sense of loss or *missing in action*. The person was telling 'it' from his or her perspective and in relation to the perspective of others. The person told his or her stories from the perspective of their present context.

The acts of telling of these personal stories were important personal records because they reflected contexts, meaning of self, the record and others. The person was cognisant that they could not remember where something was or where they were. It was a lost moment.

The processes and techniques implemented in co-creating personal records were adapted to the person being interviewed as appropriate to the cognitive issues experienced by the person. The effectiveness of personal records as representations was influenced by how the person's stories were framed. This framing included considering communication processes, aesthetics, images, quantity and size of text on a page, multiple ways of reviewing and understanding the meaning of the vignettes. A personal story retold by a person and in situated contexts

retained the essence of the story. The vignettes were small stories which were relatively stable in terms of how these stories were retold. The way stories were told and the associated meaning was contextual. The person decided what story was told and to whom. This interpersonal process allowed the person to mediate their own experience, of the story as well as how others might experience the story. Co-creating and reviewing person-centred records created representations of those stories. Each telling, due to the nature of situated contexts, was also a unique experience. Reviewing the stories was a way of understanding how stable the stories were in relation to contexts and the categories of meaning.

The co-created records were social and material objects which through their physical presence became an extension of self. So, while the co-creation of person-centred records was an expression of self, the manifestation and making explicit these representations of self also impacted on the situated context and consequently their embodied experiences. In addition it needs to be acknowledged that for the archival researcher, this understanding of story as voice and as knowledge of self is filtered by the person's emotional affect and feelings, by their spiritual beliefs and values and by their philosophical positioning through knowledge and experience.

### **6.3.3 The situated context was social and material**

People's situated contexts were not only represented through their stories and knowledge of self, but also through their physical and social contexts. It was central to developing the person-centred record, that the social and material contexts of people were understood accommodated and incorporated. The person-centred record was both an embodied experience and an extension of self.

For the people who participated in this research, the day-to-day experience of personal recordkeeping was highly contextualised. Of these contexts, dementia was a diagnosis as well as the disease. Dementia was a dominant event which accentuated and accelerated the changes in self, identity, other contexts and relationships with people as well as the keeping of meaningful records. People were conscious of the effect of dementia on their own behaviour and how it was or might be perceived by others. The person's experience of dementia affected their sense of self, identity, independence and agency. Each person acknowledged not only that their capacity was being questioned by some people, but that decisions were also being made by others on their behalf, based on these perceptions of capacity. These decisions were not malicious but rather influenced by the roles that others took on or played in caring for the person with dementia.

Contexts were dynamic spaces where participants converged with others socially and through culture. The relationships people had with others and with personal recordkeeping were shaped and constructed through all their contexts as they converged past, present and future.

There were many personally meaningful records present to the person in their home. There were also meaningful records which were not so apparent. Each person had stories for all the personal records present and absent. Where there were material records, the record's stories were not recorded. The stories were present to the person but absent to others until shared.

These personal stories were not recorded externally. These stories and each telling of the story were also personal records. These stories were not just memories of the records. These stories were acts of repositioning the record in the here and now; sometimes with implications for the person's future or effect on the past.

The person's situated context was reflected in the nature of personal recordkeeping in this complex continuum of time, people and events. The more obvious manifestation of personal recordkeeping was in the records as material and social objects that each person kept in their home. Material objects were those people or things which constituted each participant's situated contexts. The situated context in terms of remembering and representing self extended beyond the present and immediate environment. These contexts included family and friends, photos, paintings, and the home.

These dimensions of the situated contexts were many and dynamic. Participants were agents in that they were able to affect their material and social environments and they were also affected through changes in these. The social and physical dynamics have consequences for the other dimensions reflected in the model. Being in control or not being in control had an emotional, spiritual and philosophical impacts. Changes in the physical world could affect the person's embodied experience, their level of agency may affect their expressions as extensions of self. For the archivist in this context, knowledge of the material and social context was essential. Further, the archivist needed to understand the dynamics between these aspects and the other dimensions.

#### **6.3.4 Extensions of self through relationships with records**

When theorising the record and its meaning, it was possible to understand how records which are created or controlled by any other person or organisation may have meaning and affect. The relationship between person and record was even more powerful when the record in question, be it a story or object, affirmed or conflicted with a person's own perceptions of the world and sense of self.

Personal belongings were meaningful records due to the nature of the relationships represented in the object. The object became a record for an individual by association; by nature of the meaning they constructed in relationship the record. These records were not always in the individual's possession, yet the person identified with the record in ways which supported their own sense of self. The records reflected dimensions of the person's identity as a broader situated context which extended beyond their immediate or physical environment. These records behaved socially as an extension of self.

If there is disparity between the way the person perceived the record as an extension of self and their embodied experience, this is when records can be considered to be 'behaving badly'. In co-creating the person-centred record it was fundamental that these records 'behaved well'. I found that working consciously with the dimensions of physical, emotional, spiritual and philosophical assisted in coherence in embodied experience and extension of self.

### 6.3.5 The meanings within the person-centred record

The applied research processes supported storytelling, co-creating and reviewing vignettes with individuals. These techniques in turn facilitated mapping the content, associated meaning and relationships to personal stories as records, as well as to meaningful objects. Co-creating these records of self was an act of facilitating agency in a way that I would describe as calibration. Calibration in this sense was how an individual negotiated their philosophical position, through the telling and sharing of stories, with regard to personal knowledge, values and beliefs. Philosophical positioning, in personal stories, reflected how and why the individual came to think the way they do about the world.

Telling and reviewing vignettes illustrated how personal records had socially constructed meanings in relationship to people and events through time. The participants and the stories they told were located in the present. Even if the story was of a past event it was still being experienced and explained through who the person is now. Personal stories reflected an embodied experience of life which goes beyond the here and now. Personal stories reflected the philosophical approach the person took to explaining the world around them in light of their own experience. Philosophical positioning reflected their lesson of life, personal values and beliefs around how people should be treated generally, and in turn how they expected to be treated.

Meaning was expressed through different ways of knowing. Knowing was highly nuanced in the concepts used to define or describe stories, personal records or process of co-creating. Knowing was a tacit and embodied experience. Knowing was a recognition of self in the personal records co-created. The embodied experience was a bridge which traversed and challenged the philosophical boundaries of mind versus body. Co-creating personal records was like creating placeholders in personhood, context and time. Recordkeeping was an evidencing but it was not the evidence. Evidencing personhood through personal recordkeeping was complex and multi-dimensional. Evidencing personhood was more discrete than personal recordkeeping as a concept.

There were types of stories and personal records which reflected personhood for the person. The records that supported personhood were co-constructed as a social process in which the person not only had the opportunity to voice their stories but felt they had been listened to. These records were person-centred in that they manifested a personal narrative and resonated with the person's sense of self and meanings constructed within the relational context. Meanings were expressed through the relationships with personal stories and with the records representing the stories. Meaning was not fixed. Meanings were revealed through co-creating personal records as an ongoing process. Meaning was embodied in how the record was co-created as well as the record in its representation. As was the case with personhood, person-centred records were never finished but being continuously re-experienced.

These findings revealed the importance of understanding the embodied experience which incorporated the spiritual, emotional, physical and philosophical dimensions holistically. This aspect is about developing practice in which the archivist understands the philosophical



position of the people they are working with. It is this knowledge of how they would like to be treated which concerns their needs in personhood.

### 6.3.6 Making sense of themselves in the world

In telling their stories and reviewing vignettes, participants engaged in a process of making sense of themselves in the world. Interpersonal and intrapersonal processes assisted this expression of the philosophic dimension. These insights were core to explicating the philosophical dimension of the Experiential Model of the Person-Centred Record.

The vignettes we were co-creating differed to the personally meaningful records which already existed. We were co-creating new records of those small stories which reflected the unique perspectives of individuals from where they stood in the present. This activity reinforced for me how these records were person-centred. The personal story *was* the record, irrespective of the format: oral or recorded. If personal stories are the way we know ourselves and make sense of the world<sup>443</sup> then these records we were creating were also an extension of our personal knowledge; who we are and how we understand the world to be. The sharing of personal stories and reviewing vignettes were techniques for studying the inseparable dimensions of story, situated context and meaning.

Personal stories were being told for the benefit of self; to build self-esteem and reinforce their perception of self. Personal stories reflected how the person positioned himself or herself in multiple contexts; past, present and future. Personal contributions were reflected through personal stories of work, personal knowledge and life learning. Personal stories reflected the disjunct in or communal values and beliefs within shared communities.

The stories reflected personal relationships to other stories, people and events. The personal stories reflected the person's contributions outside of their immediate context. The personal stories reflected the personal relationship to material records, both present and absent. There were stories about the stories in the co-created records. The stories encompassing the records were adapted to the situated contexts and other participants in the storytelling event. Person-centred records were peoples' stories as vignettes; they were a powerful tool for making sense of self through their telling and recording was the physicalisation of their personhood embedded in the stories.

### 6.3.7 Being affected by and affecting records

Peoples' situated context was continuously changing and being constructed; so too were relationships to personal stories and records. It became evident through this research how a person could be affected by their stories and records of self and in turn they could also affect their own memories, stories and identity through records. The stories and records had affective properties.

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<sup>443</sup> D. P McAdams, "Personal Narratives and the Life Story," in *Handbook of Personality, Third Edition: Theory and Research*, ed. Oliver P. John, R. W. Robins, and L. A. Pervin, 3rd ed. (New York: Guilford Press, 2008).

People made decisions about what to keep and what to dispose of in response to life events and relationships. They accorded photos, as records, with multiple meanings. They explicated these personal records. I observed how they engaged in a processes of reconciling past experiences with current knowledge of self. It was a reflective and reflexive process. They often saw things differently in retrospect and understood their past actions.

Telling, recording and reviewing meaningful records made tacit, to some degree, the embodied experience. It is the person, who through their being, embodies the experiences and creates those connections, physically and emotionally. The way people felt about their personal stories and record influenced the way they felt. In turn, how they felt influenced the way they worked with and used records. It is as important to attend to the emotional needs of the person as well as the recordkeeping requirements. Empathy would require the archivists to put themselves into the shoes of other in order to generate insight into how people are being affected. The archivist co-creating person-centred records needs to use emotional awareness and seek to understand how participants are being affected by and affecting records.

### **6.3.8 People making decisions about the ‘rightness’ of the record**

In order to understand the meaning of records it is essential to understand the stories they represent. The capacity of co-creating records, as a process, to represent the person and their perspectives, determined the quality of the relationship between the person and their records. The story and its co-created recording was an extension of self in that it was ‘a part of the person on a page’. Reviewing vignettes was a process in which the storyteller could evaluate how well the recorded story reflected their own personal truths. Personal records were authentic because they were a means of self-expression and reflected personal truths or reality.<sup>444</sup> Personal recordkeeping was a dialogic process.

The co-creation of personal records resulted in altered perspectives of self and other. Co-creating personal records was empowering because the records afforded agency for the person to affect as well as be affected by that which is recorded. The person’s encounter with and response to the record was always ‘right’. The embodied experience was the person’s truth. Co-creating personal records was a reflexive process for both participant and researcher. Co-creating and evaluating the personal record afforded decision-making. Co-creating personal records created a communal and shared activity. Co-creating personal records created shared realities.

The person made decisions about the ‘rightness’ of the co-created personal records. Decision-making was a social process. The person chose to tell a story and the context in which the story was told. The significance of a story or record as material object was not evident in its physical manifestation alone. Decisions were not always ‘voiced’ through the text. Decisions were made explicit through selectively sharing a story with a certain listener at a particular time

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<sup>444</sup> Gergen, *An Invitation to Social Construction*, 2009.

or through a particular medium. The person and the listeners were affected by the story and its record.

Each individual was making decisions about the stories. Participants were representing themselves in particular ways to particular people, through their stories in the social contexts. In recording these stories by co-creating vignettes with the person, it was possible to represent their perceptions of life and self. These records were person-centred in that they focused on representing the person's perspectives and were concerned primarily with the needs of the individual in effecting their personal truths.

Reviewing personal stories through co-creating records were processes for facilitating decision-making both for participants and for me as the researcher. Participants read the vignettes and corrected them with me. If records did not reflect peoples' perceptions of the stories (as perceived in the present) they would modify the story or reflect on its meaning. We could make changes according to the person's feedback regarding the vignettes. We co-created new vignettes in light of those conversations.

Co-creating and reviewing vignettes provided a detailed and systematic process for studying the participants' relationships to their stories and the records. When the representation was right for the person, it reflected the person's own unique truth. In this sense the person did not distinguish between the story contained in the record and the record itself; the narrative and physical representation belonged to one and the same thing. The implications of this phenomenon in the context of this research, means that the record and its content are an embodied experience. The record's power in affecting a human being caused me to ask questions regarding what should be recorded and the direct impact of that representation.

Ethical wayfinding in archival practice supports working with people and making decisions about them and their records. Each person is unique. Archival work cannot be prescriptive in the context of co-creating person-centred records. Ethical wayfinding is a journey and a practice for knowing people and navigating person-centredness. The practice takes the archivist through peoples' embodied experiences; holistically through spiritual, emotional, philosophical and physical dimensions and through co-creating records as extensions of self.

The rightness of the record is about how personhood is reflected and represented in the record. Decision-making about the records is personal, interpersonal and holistic. Ethical wayfinding is working with people in making decisions about rightness of the record in an important process. Decision-making acknowledges and is built on all the dimensions in the Experiential Model of the Person-Centred Record.

### **6.3.9 In summary**

In the preceding eight sections the concepts related to the dimensions within the Experiential Model of the Person-Centred Record were identified and discussed. The human relationship to person-centred records was theorised as an embodied experience and an extension of self. This experience of the person-centred record was presented within the dimensions of spiritual, emotional, philosophical and physical. Engaging with these dimensions required the

archivist to understand and work within peoples' situated contexts. Stories were identified as integral to the expression of voice and self-knowledge. The archivist needs to affirm the social as well as material nature of records as part of persons' lived worlds. The human relationship to records was an extension of self. Personal archivists are integral to the co-creation of meaning within the records as a representation of self, and supporting people in making sense of themselves in the world. Additionally there is emphasis placed on how people affect records and a mindfulness in relation to how people are affected by records. Decision-making is a process, which includes ethical wayfinding, for navigating the rightness of the record.

As these concepts are experienced dynamically in the person-centred record, archivists need to develop theoretical as well as situational knowledge about people. Archivists, when co-creating person-centred records needs to work with the people in their social and material contexts. Creating records is a process of physicalising the stories of self and ways of knowing the world which is an embodied experience. People experience records through emotions and feelings. Records have the capacity to affect and also be affected by people as agents. The spiritual dimension highlights the importance of connecting with people, building relationships based on shared values and beliefs. Personal identity and philosophical approach to life is constructed through the way we know the world, our knowledge and learning.

## **6.4    *The Experiential Model of the Person-Centred Record:***

### ***Further Notes***

Before concluding this chapter it is important to make some further notes in relation to the Experiential Model of the Person-Centred Record. The Experiential Model of the Person-Centred Record, as depicted in Figure 33, is a grounded theory which is conceptual and integrates dimensions of human experience in relation to person-centred records.

Additionally, the model is metaphoric as an emergent theory for future archival practice. Contexts in this research were situated in perspectives of the person with early stage dementia, and through the study of co-creating person-centred records, and hence are inclusive of the material world.

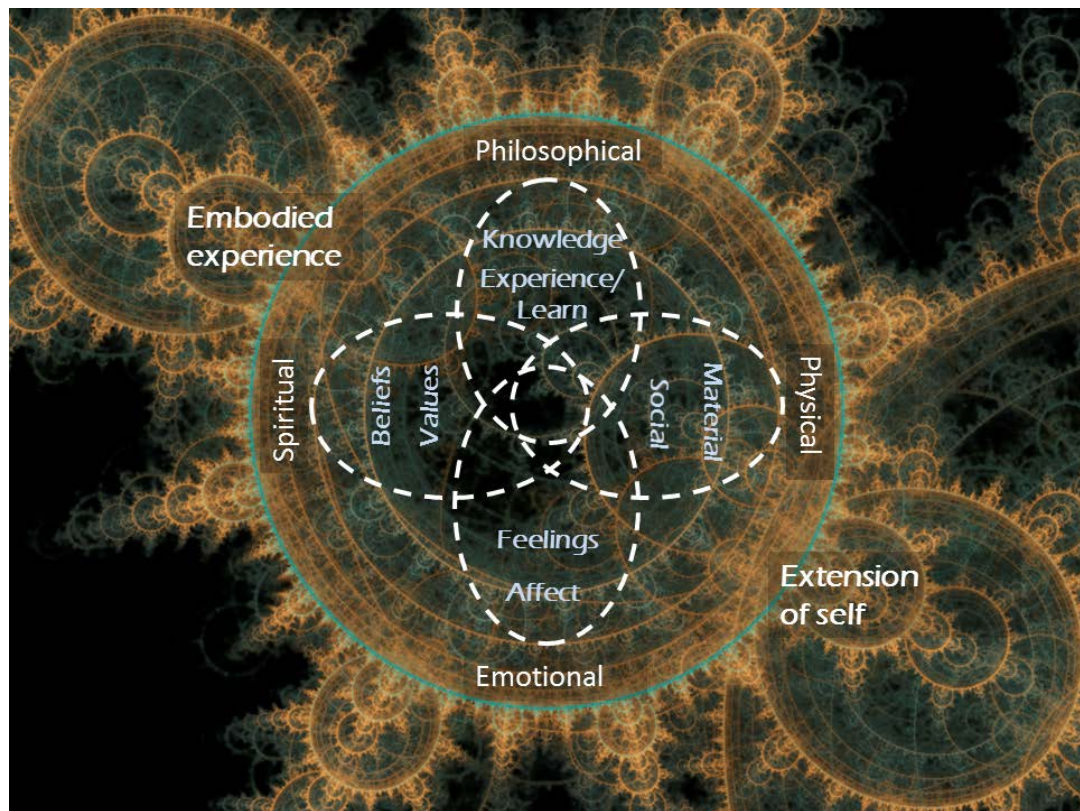
Human beings have long used metaphors to help make sense of complex concepts which may resist definition. The act of using a metaphor is itself an interpretive act. Metaphors are used as figurative language to compare "two different and disparate subject matters".<sup>445</sup> "Every metaphor, provided it be a good one, has a direct appeal to the senses, especially the sense of sight, which is the keenest...Metaphors drawn from the sense of sight are much more vivid, virtually placing within the range of our mental vision objects not actually visible to our sight."<sup>446</sup> Cicero described metaphor as appealing to pathos. Metaphor has the ability to name the unnamed, make meaning clear. There must be some semblance for metaphors to be

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<sup>445</sup> "Metaphor," *Wikipedia, the Free Encyclopedia*, accessed February 6, 2013, <http://en.wikipedia.org/wiki/Metaphor>.

<sup>446</sup> M. T. Cicero, *Cicero: De Oratore.*, ed. D. Mankin (Cambridge: Cambridge University Press, 2011), 155, [https://books.google.com.au/books?id=lmU2Rm2Oo\\_8C](https://books.google.com.au/books?id=lmU2Rm2Oo_8C).

useful. The metaphor is substituted for the concept to which it refers.<sup>447</sup> Like metaphors, models are neither theory nor real world; they are independent of both these domains yet can be implemented to explore both theory and the real world.<sup>448</sup>



**Figure 33 Experiential Model of the Person-Centred Record**

The Experiential Model of the Person-Centred Record is embedded with the image of a fractal. Both the model and the image are metaphors for the complexity and recursiveness of personhood in relationship to person-centred records. The Experiential Model of the Person-Centred Record creates a unified arena which serves to redress the dualistic notions of mind and body and to extend the perception of personhood as being socially constructed in relation to people and their contexts. The model creates points for triangulating perspectives and for exploring co-creating person-centred records. “The term triangulation is taken from land surveying. Knowing a single landmark only locates you somewhere along a line in a direction from the landmark, whereas with two landmarks (and your own position being the third point of the triangle), you can take bearings in two directions and locate yourself at their intersection.”<sup>449</sup>

<sup>447</sup> R. F. Collins, *The Power of Images in Paul* (Collegeville, MN: Liturgical Press, 2008), [https://books.google.com.au/books?id=qsNL3Zip6DAC&printsec=frontcover&source=gbs\\_ge\\_summary\\_r&cad=0#v=onepage&q&f=false](https://books.google.com.au/books?id=qsNL3Zip6DAC&printsec=frontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false).

<sup>448</sup> M. S. Morgan and M. Morrison, *Models as Mediators: Perspectives on Natural and Social Science* (Cambridge: Cambridge University Press, 1999).

<sup>449</sup> M. Q. Patton, *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*, 4th ed. (Thousand Oaks, CA: SAGE Publications, 2015), 661, <https://books.google.com.au/books?id=CM9BQAAQBAJ>.

The person-centred record was co-created ‘in the line of sight’ of the people interviewed and the researcher. We were sharing the same narrative content as a co-ordinated action, but were each bringing a different understanding and experience of this record co-creation. Gergen explains that understanding others, is a process both difficult and fraught. Using a social constructionist lens he articulates how

meaning is achieved in coordinated action...we understand each other when we effectively coordinate our actions – drawing from traditions in ways that are mutually satisfactory...In each of these relationships we have developed a unique pattern of understanding. In constructionist terms, we have created many different realities together, along with value, rationalities, and practices of relating. Although these realities may overlap in important ways, they are all quite unique. As a result, we carry the capacity to live in multiple worlds.<sup>450</sup>

For the archivist, the model provides a metaphor and conceptual dimensions for working with people and their records in person-centred ways. Learning and understanding about how our unique ways of knowing the world converge or digress is important. The Experiential Model of the Person-Centred Record is not only about the way we understand the perspectives of people, it is also a reminder to challenge the archivist’s own experiences as possible assumptions.

## 6.5 Conclusion

The Experiential Model of the Person-Centred Record is a second generation grounded theory constructed within the situated context of co-creating person-centred records with people diagnosed with early stage dementia. The concepts embedded within the model are underpinned by theories coherent with postmodern and social constructionist theory and practice. These theories add new knowledge underpinned by social constructionism to understandings of the way records may be co-created and used to support personal memory, identity and personhood.

The theory of the Experiential Model of the Person-Centred Record supports exploring personhood in stories of self and co-creating records through taken-for-granted assumptions. This grounded theory draws special attention to the way personal storytelling and the co-creation of vignettes, when analysed, was an embodied experience for the participants in this research. Personal storytelling was a way of making sense of self in the world. This embodied experience was composed of multiple and complementary dimensions. Through social processes participants were actively engaging in externalising their stories of self as material representations. Participants were philosophical in how they applied their personal knowledge to contexts: past, present and future. Personal knowledge reflected individual’s values and beliefs and how this informed their social connections. The processes for sharing, representing and reviewing stories as vignettes highlighted the way these records and their meaning were co-constructed; it was an emotional experience where people were affected by

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<sup>450</sup> Gergen, *An Invitation to Social Construction*, 2009, 111.

the records being co-created and also able to affect the co-creation process. This chapter is the third and last chapter in which the findings of the grounded theory study are reported. The key message arising from these findings is a grounded theory which offers a conceptual representation of dimensions associated with co-creating person-centred records.

## 7 Discussion: A Social Constructionist Theory of the Experiential Model of the Person-Centred Record

### 7.1 Introduction

The research aims identified in Chapter 1 of this thesis guided me in how this research was designed and the problem space explored.<sup>451</sup> In Chapters 3 and 4 I explicated how this research design supported working with people and their data. The overarching aim of this research was to construct a second generation grounded theory of co-creating person-centred records in the context of early stage dementia. Further, to explore how second generation grounded theorising contributes to archival theory and possible implications for practice. In order to address this research aim, four exploratory questions were asked:

1. How do individuals perceive what is important in creating their own personal records in their current context of early stage dementia?
2. How do people represent their own memories and stories in ways that support the integrity of their identity and memory?
3. How is meaning supported and sustained in the process of co-creating records?
4. How do we achieve a rich understanding of the ethical issues and processes involved in this kind of record co-creation?

In Chapters 4 and 5 I discussed person-centred records, as both the processes for their production and the vignettes as products of co-creation. Social constructionism, drawn from psychology and social psychology, was adopted as the theoretical lens for studying interpersonal relationships and the making of meaning through co-creating records. This perspective is congruent with the second generation grounded theory approach and constituent social constructionism which influenced the methods implemented and lenses for discerning these micro-level interactions. Importantly, within this applied archival research, and as explained in Chapters 2 and 3, the methodology and theoretical lens were compatible with the postmodern and philosophical underpinnings of records continuum thinking.

In Chapter 6 I addressed the principle aim of this research by generating a social constructionist grounded theory of co-creating the person-centred record and the Experiential Model of the Person-Centred Record. The model is a “conceptual interpretation of the data” and a theory grounded in the findings.<sup>452</sup>

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<sup>451</sup> K. Charmaz, “Grounded Theory,” in *Qualitative Psychology: A Practical Guide to Research Methods*, ed. J. A. Smith, 2nd ed. (London: SAGE Publications, 2007), 85, <https://books.google.com.au/books?id=OEBdBAQAQBAJ>.

<sup>452</sup> A. Strauss and J. M. Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (Thousand Oaks, CA: SAGE Publications, 1998) as cited in M. Birks et al., “A Thousand Words Paint a Picture: The Use of Storyline in Grounded Theory Research,” *Journal of Research in Nursing* 14, no. 5 (September 1, 2009): 410, doi:10.1177/1744987109104675.



In this thesis I have articulated *how* person-centred records were co-created implementing a second generation grounded theory methodology, innovative methods and techniques for working with participants and their data. The findings explored the function and meaning of these records in supporting memory, identity and personhood. Postmodern theories of personhood were fundamental influences in the person-centred approach I took with people and their records.

In Chapter 7 I address the fourth research question by discussing how this second generation grounded theorising and reflexive practice contributes to understandings of ethics in theory and practice. Chapter 7 is constructed around a discussion of the Experiential Model of the Person-Centred Record, reflecting postmodern and ethical qualities of this second generation grounded theory research in which the co-creation of records were explored as

“a” form of witnessing and memory making, a particular way of evidencing and memorializing individual and collective lives...Whatever function they are performing, their usefulness as evidence is bound up with how they are created, how they have been captured in recorded form<sup>453</sup>

This chapter is structured around three main sections:

- Section 7.2: The Experiential Model of the Person-Centred Record is positioned as a social constructionist grounded theory and key contribution of this research.
- Section 7.3: Is a discussion in which this second generation grounded theory of the person-centred record is evaluated as a postmodern theory and model, built through a social constructionist lens and theories of psychology and social psychology.
- Section 7.3: Postmodern ethics and reflexivity are discussed in relation to the findings of this study and methodological wayfinding as it has been described in this applied research.

## **7.2    *The Theory of Experiential Model of the person-centred record***

This grounded theory research achieved the aim of constructing a second generation grounded theory of the person-centred record. As indicated in Chapter 2 of this thesis there is a need for archival and recordkeeping processes to be extended and applied into new and emergent contexts. Of these contexts, working with people diagnosed with dementia is an important one. This type of research and the other relevant grounded theories derived from grounded theory or other processes, are non-existent. As such, a second generation grounded theory approach was adopted in order to explore a new and emergent context in archival research. This section includes the following sub-sections:

- Contributions of this theory and the model
- Addressing the research aims and questions.

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<sup>453</sup> McKemmish, Upward, and Reed, “Records Continuum Model,” 4447.

### 7.2.1 Contributions of this theory and the model

The findings from this research, which led to this new grounded theory, are important to report and communicate in relation to future practice. The theory and model bring together themes and concepts identified through analysing data grounded in the context of co-creating person-centred records with people diagnosed with early stage dementia. This theorising explains, through a social constructionist lens, the embodied experience of telling and recording personal stories in order to understand how they support memory and identity. The theory also addresses the first three research questions restated in Section 7.1, by explaining stories which were shared by participants as having particular meaning in this study; through their situated contexts, the story as content and the meaning of these stories as records.

This social constructionist theory of the Experiential Model of the Person-Centred Record reflects its inherent postmodernist thinking, social constructionist lens and participatory epistemology explicated in Chapter 2. A participatory epistemology was described as a way of understanding knowledge as being co-constructed within social contexts. The grounded data and findings were progressively interrogated throughout this thesis, in light of these theoretical positions in order to address the first three research questions. In this research, postmodern theories of personhood, emphasised the psychological and social processes of storytelling which are implicated in the construction of meaning. As such, these theories of personhood influenced researcher practice in working with people in this research, the processes for producing and analysing person-centred records.

This theory of the person-centred record was constructed and defined by representing stories of self in relationship to others, as shared by participants, and then analysing these for the tacit, existential experience as well as explicit meaning of these stories. This theory was built on data grounded in the situated context. It contributes to new knowledge of the ways in which human beings experience records, as a social process of physicalising tacit knowledge, values and beliefs.

Person-centred records were representations of complex stories which revealed layers of meaning, as described in Chapters 5 and 6, and conceptualised in the Experiential Model of the Person-Centred Record. Though these layers of meaning have been described individually within a range of literature, as described in Chapter 6 the way they have been brought together in this model is unique. This grounded theory creates a bridge between the internal or existential experience and the physical production of the record. This research addresses the need to study and understand the material world within social constructionism as well as in archival science as described in Chapter 6 Section 3.

This theorising of the social and material world is strongly underpinned in social constructionism which emerges from the disciplines of psychology and social psychology. Importantly, social constructionism provided the theory, ontology and language with which to describe and explain the phenomena and findings within this research. These were emotional experiences. This second generation grounded theory was conducted using methods and techniques suited to studying the person-centred records not only as a material object but as the participants' embodied experiences.

### 7.2.2 Addressing the research aims and questions

Answering the research questions stated earlier provided the grounded data and findings with which to construct the resulting grounded theory. Addressing the fourth research question informed the second part of the research aim, in which I explored the implications of those research findings and subsequent grounded theory for archival theory and practice. The rest of this section provides an overview of where in thesis the research questions were addressed and how the findings contributed to building a theory of co-creating person-centred records.

A fundamental social constructionist assumption is that storytelling is a dynamic interpersonal process through which we construct and support our identities. The creation of vignettes and life books were techniques for addressing the first research question:

How do individuals perceive what is important in creating their own personal records in their current context of early stage dementia?

The vignettes, as described in Chapter 4, were stories of meaningful people and events. Importantly, personal stories as records did not always make explicit why certain stories were meaningful to people. The stories and their meaning for individuals needed to be examined in ways that revealed sometimes what was beyond words.

Eliciting stories and the various types and categories of meanings, both tacit and explicit required the adoption of methods and techniques suited to exploring participant contexts and the human experience. In addressing the second research question the study needed to go beyond the recorded vignettes:

How do people represent their own memories and stories in ways that support the integrity of their identity and memory?

The categories of meaning as explicated in Chapter 5 were determined by analysing not only the personal stories recorded in vignettes but through mapping of personal contexts and in-depth discussions regarding the meaning of stories.

The theory and concepts in the Experiential Model of the Person-Centred Record, as explained in Chapter 6, address the third research question:

How is meaning supported and sustained in the process of co-creating records?

The theory and concepts in the model, point the user, to look for explanations about where the concepts and their meanings are described in each storytelling event. These storytelling events are performed specifically in response to people and in situated contexts which are always changing. Storytelling events were social events and through the construction of records also material.

### 7.2.3 In summary

In the first part of this chapter I discussed the key contributions of this thesis which include: innovative methods and techniques in second generation grounded theory, person-centred approaches to working with people, their data and records, and co-creation of records via complementary techniques for generating and analysing data. The following section reviews

this social constructionist grounded theory and model with respect to the theories implemented and decisions made throughout this research.

### **7.3 Evaluating the Construction of this Second Generation Grounded Theory**

Record co-creation lies in between the experience of telling and recording the story. The findings of this research and the Experiential Model of the Person-Centred Record explicated the complexity of co-creating person-centred records. This social constructionist grounded theory and conceptual model explored record co-creation as part of a continuum. This co-creation process integrates the internal and *embodied experience* with the construction of a record as an *extension of self* as described in Chapter 5.

This second generation grounded theory emerged from within a postmodern archival paradigm and context. Building this theory was underpinned by key influences: postmodernism, social constructionism, a participatory epistemology and theories of personhood as discussed in Chapter 2. It was human and social processes we were engaging in when co-creating person-centred records: shared memory-making, representing personal stories as vignettes and exploring their meaning and situated contexts.

Through this research I studied in detail, those processes and decisions implicit in Ketelaar's term "archivalization" (introduced in Chapter 2) defined as the "conscious or unconscious choice to consider something worth archiving...determined by influenced by cultural and social factors".<sup>454</sup> These processes precede archiving and acknowledge the role of the archivist in all the recordkeeping processes including their purposeful creation.<sup>455</sup> Purposeful creation was a human activity and a focus of this research.

As the reflexive researcher I was challenged to make explicit and evaluate those archival decisions. Due to the exploratory nature of this research, a primary decision and possibly the most influential was choosing to adopt a second generation grounded theory methodology, founded on constructivist and social constructionist thinking. As introduced in Chapter 2 and explained in more detail in Chapter 3, social constructionism is differentiated from constructivism in that it shifts the focus from an individual cognitive experience, as is the case with constructivism, to a worldview where meaning is created within social contexts and relationship to other people.<sup>456</sup> Working with people with early stage dementia and co-creating person-centred records, emphasised the need to address personhood at a theoretical level and in practice which is consistent with the postmodern position.

The findings of this research highlighted the social and interpersonal nature of constructing reality and records as a product of these interactions. Social constructionism became the predominant lens used for the systematic and in-depth analysis of data. Much like the

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<sup>454</sup> Ketelaar, "Tacit Narratives," 133.

<sup>455</sup> Ketelaar, "Archivalisation and Archiving," 57.

<sup>456</sup> Young and Collin, "Introduction: Constructivism and Social Constructionism in the Career Field."

magnitudes described in the film *Powers of Ten* (discussed in Chapter 2 Section 3), it was necessary to situate the perspectives and position as the focus of this second generation grounded theory research. Though I acknowledge that records are created within broader societal contexts as conceptualised within records continuum thinking; applying a social constructionist lens within this research amplified the complex nature and meaning of the concept co-create.

Records continuum theory and structuration theory (a sociological theory), as discussed in Chapter 2, provide potential lenses for studying how *social structures* influence the role of records in the lives of people.<sup>457</sup> This type of social analysis would focus on dualism of agent and structure. Though social structures were important influences within the participants' broader situated context, the findings of this research revealed the inherent blurredness and complexity of the micro-level interactions between individuals in relationship to co-creating person-centred records.

Working with people and co-creating records required alternate lenses drawn from psychology and social psychology for studying interpersonal relationships and making meaning through creating records.<sup>458</sup> This perspective is congruent with the second generation grounded theory approach and constituent social constructionism which contributed methods and lenses for discerning these micro-level interactions. Importantly, as argued in Chapter 3, within this applied archival research the chosen methodology and theoretical lens were compatible with the postmodern and philosophical underpinnings of records continuum thinking.

Second generation grounded theory provided systematic and iterative processes for generating and analysing data. The social constructionist lens focused on how we as human beings make meaning in relation to self and others. The use of data sources such as visual media and artefacts generated rich resources “to which an individual or group may assign meaning” even though they are not traditionally sought out in grounded theory research.<sup>459</sup> In this thesis, social constructionism created an important lens into how we co-created and perceived personal knowledge, and represented this as stories and records of self. This is consistent with Charmaz's expectations of grounded theory.

When born from reasoned reflections and principled convictions, a grounded theory that conceptualizes and conveys what is meaningful about a substantive area can make a valuable contribution. Add aesthetic merit and analytic impact, and then its influence may spread to larger audiences.<sup>460</sup>

The findings of this second generation grounded theory research inform future practice in the creation of person-centred records. The theory of the Experiential Model of the Person-

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<sup>457</sup> S. Oppong, “Between Bandura and Giddens: Structuration Theory in Social Psychological Research?” *Psychological Thought* 7, no. 2 (October 22, 2014): 111–23, doi:10.5964/psych.v7i2.104.

<sup>458</sup> This concept of co-creation is consistent with Hurley's discussions of parallel provenance, as described in Chapter 2. Hurley provides insight into the complex nature of describing the co-creation of records and multiple meanings.

<sup>459</sup> Birks and Mills, *Grounded Theory: A Practical Guide*, 2015, 81.

<sup>460</sup> Charmaz, *Constructing Grounded Theory*, 338.

Centred Record contributes to archival theory by focusing on and illuminating the human experience of the record as a co-creation and social construct. This was empirical research in an applied context. The “goal of empirical research – [is] to observe phenomena in the social world so as to generate knowledge about these phenomena.”<sup>461</sup> I would argue that this research has achieved the standards of quality and rigour required of this type of empirical research.

This social constructionist grounded theory of the Experiential Model of the Person-Centred Record, explicated in Chapter 6, was progressively shaped and explored through the study of situated contexts of people diagnosed with early stage dementia. The application of diverse methods, techniques and reflexive practice created unique ways for understanding the multiple perspectives when co-creating person-centred records. The findings of this research highlighted the dimensions and elements of personhood and person-centredness which were a complex dynamic of knowing the other in relation to self. (Described in Chapter 2) Person-centredness in this study meant that the person and their perspective was the focus of co-creating the records as a research product. There were two units of analysis here: the person and the record co-creation. In this instance I am highlighting how the human relationship to records is an integrated and holistic experience. Co-creating person-centred records for the purpose of understanding and supporting personhood for the person with dementia was personal. The quality of the theory of the person-centred record must be evaluated within the context of its construction within this research and in the lives of people.

The construction of this second generation grounded theory is evaluated under the following headings:

- Quality in this social constructionist research and this study of co-creating records.
- Person-centred research: The importance of personhood and personal storytelling
- Sharing personal stories and temporality
- Making meaning and representing perspectives
- Postmodern challenges of recording memory and stories of self.

### **7.3.1 Quality in this social constructionist research and this study of co-creating records**

It is generally agreed that the criteria for evaluation of qualitative inquiry should be appropriate to the paradigms, methodology and situated in the unique context of the participants in this research.<sup>462</sup> The quality and outcomes of this social constructionist research were very much dependent on my own practice as the researcher. Lincoln and Guba urge that

the quality (rigor) criteria for an inquiry cast in relativist ontological terms, in transactional/subjectivist epistemological terms, and in hermeneutic/dialectic terms must be appropriate to such a paradigmatic framework; they cannot be objectivist or

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<sup>461</sup> H. Bhattacharya, “Empirical Research Within Qualitative Research,” in *The SAGE Encyclopedia of Qualitative Research Methods*, ed. L. M. Given (Los Angeles, CA: SAGE Publications, 2008), 254.

<sup>462</sup> Lincoln and Guba, *The Constructivist Credo*, 70.

foundational... Whatever criteria emerge, they must also reflect the moral, ethical, prudential aesthetic, and action commitments of constructivism.<sup>463</sup>

The findings presented in Chapters 4 to 6 demonstrate that these aspects of constructivism and social constructionism were maintained and achieved throughout the project. As the researcher I was an integral part of the research. As much as I was studying this particular context, I was also under scrutiny. Though the social constructionist lens infers that the researcher is always present, I was challenged to be mindful of my own position in relation to people and in co-creating their records. Reflexivity was played out through the practice of negotiating and representing complex and plural perspectives. This finding regarding the importance of and nature of reflexive practice in co-creating personal records extends current writing on the participatory epistemology within archival science. It provides salient insights regarding the complexity of capturing and recording what Hurley describes as parallel provenance.<sup>464</sup>

A participatory epistemology was discussed in Chapter 2 as an emerging characteristic of postmodern paradigms. The postmodern perspective is congruous with a “participatory epistemology that replaces the “modern” principle of validity with a constructivist concept of viability. The perspective of the observer and the object of observation are inseparable; the nature of meaning is relative; phenomena are context-based; and the process of knowledge and understanding is social, inductive, hermeneutical, and qualitative.”<sup>465</sup> Postmodernism and its relationship to the construction of knowledge and understanding in *how* we think, has evolved from the introduction of constructivist thinking in psychological inquiry.<sup>466</sup>

As a researcher I was invoking voices and forms, using other ways of communicating through metaphors and representations. The reader is also being invited to have many opinions.<sup>467</sup> Throughout the thesis I have attempted to articulate the multiple perspectives and voices. Writing up reflexive research in a way that communicates the experience honestly and with academic skill is both complex and fraught. Social constructionism challenges traditional standards of scholarly writing. As Gergen explains, social constructionist writing “not only communicates content; it also invites a relationship with the reader.”<sup>468</sup>

The context of this thesis placed much weight on hearing and knowing voice through the personal stories<sup>469</sup> and co-creation of records with people diagnosed with early stage dementia. I articulated in the findings and theorising those human activities of co-creation as complex constructions situated in the shifting contexts of each participant.

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<sup>463</sup> Ibid.

<sup>464</sup> Hurley, “Parallel Provenance (If These Are Your Records, Where Are Your Stories?)”

<sup>465</sup> Sexton, “Constructivist Thinking within the History of Ideas: The Challenge of a New Paradigm” as cited in Gergen, “The Social Constructionist Movement in Modern Psychology,” 8.

<sup>466</sup> Gergen, “The Social Constructionist Movement in Modern Psychology”; Denzin and Lincoln, *The Handbook of Qualitative Research*.

<sup>467</sup> Gergen, *An Invitation to Social Construction*, 2009, 152.

<sup>468</sup> Ibid., 151.

<sup>469</sup> Jackson and Mazzei, *Voice in Qualitative Inquiry: Challenging Conventional, Interpretive, and Critical Conceptions in Qualitative Research*; Denzin and Lincoln, *The SAGE Handbook of Qualitative Research*.

The major task of the constructivist investigator is to tease out the constructions that various actors in a setting hold and, so far as possible, to bring them into conjunction – a joining – with one another and with whatever other information can be brought to bear on the issues involved...constructions are, quite literally, created realities.<sup>470</sup>

This finding about the importance of hearing and knowing voice through personal stories adds to records continuum thinking which is positioned in postmodernism (as described in Chapter 2). True to the postmodern theoretical underpinnings of this second generation grounded theory research and social constructionist lens, this thesis explored the constructions and the constructors by piecing together the complexity of the parts as described by Lyotard.<sup>471</sup> The parts were the perspectives constructed into shared realities. It was, as described in Chapter 3, a process of methodological wayfinding to co-create person-centred records within the context of the person with early stage dementia. I had determined an overarching approach, with a toolkit of methods and techniques, rather than a predefined course of action and engagement.

The nature of reflexive practice in this research was illuminated through conversations with participants and exploring their perspectives in relation to co-creating person-centred records in situated contexts. “We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices.”<sup>472</sup> Methodological wayfinding is an approach to undertaking archival research which supports working within new and emergent contexts. It provides archival researchers with a lens that incorporates multiple activities which need to be addressed in sensitive contexts and within a participatory epistemology. The way these activities are undertaken and the philosophical underpinnings impact on the quality of the research and the ethical co-creation of person-centred records.

In summary, quality in this social constructionist research was underpinned by developing reflexive practice and processes for hearing voice and co-creating person-centred records. Emerging from this study is an understanding that issues of rigour and validity require deep consideration when working with people and in co-creating records. It was important to identify meaningful concepts through analysis of data. It was equally significant to understand how that personal meaning was constructed. These findings, about how quality in social constructionist research can be attained in archival projects, will be useful for building future research protocols to investigate the co-creation of person-centred records.

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<sup>470</sup> Guba and Lincoln, *Fourth Generation Evaluation*, 142–143.

<sup>471</sup> For a more detailed discussion on Lyotard’s thinking on complexity and postmodernism see P. Cilliers, *Complexity and Postmodernism: Understanding Complex Systems* (London: Routledge, 2002), 146, [https://books.google.com.au/books?id=qHeGAgAAQBAJ&printsec=frontcover&dq=Complexity+and+Postmodernism:+Understanding+Complex+Systems+2002&hl=en&sa=X&ved=0ahUKewiF\\_srFkbDLAhUFn5QKHxEIDBgQ6AEIHDA#v=onepage&q=lyotard%20complexity&f=false](https://books.google.com.au/books?id=qHeGAgAAQBAJ&printsec=frontcover&dq=Complexity+and+Postmodernism:+Understanding+Complex+Systems+2002&hl=en&sa=X&ved=0ahUKewiF_srFkbDLAhUFn5QKHxEIDBgQ6AEIHDA#v=onepage&q=lyotard%20complexity&f=false).

<sup>472</sup> “With grounded theory, you begin by exploring general research questions about a research topic of interest. You collect data about what relevant people for this topic say and do about it...Grounded theorists’ background assumptions and disciplinary interests alert them to certain issues and processes in their data from which they can develop research questions.” Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 10.



### 7.3.2 Person-centred research: The importance of personhood and personal stories for people with dementia

As highlighted so far in Section 7.3, quality in this research was dependent on how this study was conducted; through reflexive practice underpinned by social constructionist theory and participatory epistemology. A person-centred approach focused on the perspectives of people with dementia in relation to their data; it highlighted how moral and ethical assumptions influenced researcher practice. Postmodern theories as described in Chapter 3 were integral to this context.

Personhood as described in this thesis acknowledges that the person is the maker of meaning, and, creating person-centred records is about understanding the person's sense of self. As Harré explains personhood

is to have a sense of one's point of view, at any moment a location in space from which one perceives and acts upon the world, including that part that lies within one's own skin... 'a sense of self' is also used for the sense one has of oneself as possessing a unique set of attributes which, though they change nevertheless remain as a whole distinctive of just the one person. These attributes include one's beliefs about one's attributes. 'The self', in this sense is not an entity either. It is the collected attributes of a person. The word 'self' has also been used for the impression of his or her personal characteristics that one person makes on another.<sup>473</sup>

In Chapter 2 I addressed the emergent state of research in the archival turn. The work being undertaken has implications for understanding records and their impact on personhood. However, it does not directly engage with the theories and constructs of personhood. Based on the outcomes of this study, it is likely that researchers and archival theorists will find these conceptualisations of personhood both relevant and useful to future work.

In conducting research there are well established laws, frameworks and catch cry of committees and signatories of approval all of which exist to ensure the safety of human research participants and, less explicitly, the researchers. This ethical concern for human welfare is described as a state of mindfulness. While the mandate 'to avoid doing harm' is the catch cry of ethical research practice there is the increasing expectation that particularly in some circumstances it may also be possible to "promote well-being of participants or maximise the benefits to society as a whole."<sup>474</sup>

The sensitive context of this research raised important issues regarding how people represented their memories, and stories in ways that support the integrity of their identity and memory. (Research Question 2) Postmodern theories of personhood, as discussed in Chapter 2 emphasised that we perceive self and identity through our experiences with others.<sup>475</sup> The lives of people with dementia are affected not only by the disease but "also by their personal

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<sup>473</sup> Harré, *The Singular Self: An Introduction to the Psychology of Personhood*, 4.

<sup>474</sup> M. Israel and I. Hay, *Research Ethics for Social Scientists* (London: SAGE Publications, 2006), 95.

<sup>475</sup> Stanghellini and Rosfort, *Emotions and Personhood: Exploring Fragility – Making Sense of Vulnerability*.

histories, their interactions with others, and by how they are perceived within their social contexts.”<sup>476</sup>

There is growing evidence to indicate that at least some of the negative consequences associated with dementia may be mitigated or delayed by an approach to care that respects and supports each individual’s personhood, and that facilitates its transformation and development throughout the disease...Despite its intuitive appeal, however, this approach to care is somewhat marginalized and requires further research to understand its potential impact and the challenges and opportunities associated with implementation.<sup>477</sup>

As described in Chapter 2, Kitwood was a powerful influence in developing person-centred approaches to understanding and supporting the person with dementia.<sup>478</sup> The translation of person-centred approaches into practice continues to be an ongoing concern. It requires a shift in the dominant assumptions of professionals across disciplines and of the broader community; from the biomedical model and cognitive bias to a worldview in which the person with dementia is perceived as maintaining awareness of their own situated self.<sup>479</sup>

In Chapter 4 I described the code and concept of *the world closing in* which reflected changes in the world of the person with dementia; a response to being conscious of cognitive changes and loss of control in interpersonal interactions and environment. Through the person-centred activities in this research, participants were actively reinforcing their stories of self, interactions with others and discussing their perceptions within their situated contexts. These activities have been described by O’Connor et al. as strategies for preservation of self.<sup>480</sup> Strategies are implemented and changed in response to interpersonal and environmental contexts and may include a range of behaviours which compensate for the difficulties or negative perceptions experienced. There has been some research into the impact of interpersonal communication on personhood but there is very little on the environmental contexts.<sup>481</sup>

The findings of this social constructionist research illustrated how co-creating records was a social and interpersonal process which affected each person’s immediate environment. Personal storytelling and co-creating person-centred records, as described in the findings chapters (Chapters 4, 5 and 6), were ways of connecting, hearing participant voices and their

<sup>476</sup> N. Harding, *The Social Construction of Dementia: Confused Professionals?* (London: Jessica Kingsley Publishers, 1997), [https://books.google.com.au/books?id=9ERsloy8\\_2sC](https://books.google.com.au/books?id=9ERsloy8_2sC); Hughes, Louw, and Sabat, *Dementia: Mind, Meaning, and the Person*; Kitwood, *Dementia Reconsidered: The Person Comes First* as cited in; D. O’Connor et al., “Personhood in Dementia Care Developing a Research Agenda for Broadening the Vision,” *Dementia* 6, no. 1 (February 1, 2007): 122, doi:10.1177/1471301207075648.

<sup>477</sup> O’Connor et al., “Personhood in Dementia Care Developing a Research Agenda for Broadening the Vision,” 122.

<sup>478</sup> Kitwood, *Dementia Reconsidered: The Person Comes First*.

<sup>479</sup> L. Clare, “Managing Threats to Self: Awareness in Early Stage Alzheimer’s Disease,” *Social Science & Medicine* 57 (2003): 1017–29.

<sup>480</sup> O’Connor et al., “Personhood in Dementia Care Developing a Research Agenda for Broadening the Vision.”

<sup>481</sup> L. Clare, I. Brown, and R. Pratt, “Perceptions of Change over Time in Early-Stage Alzheimer’s Disease: Implications for Understanding Awareness and Coping Style,” *Dementia* 4, no. 4 (November 1, 2005): 487–520, doi:10.1177/1471301205058304.

perspectives as an *extension of self*. The records became tangible and material representations of sometimes diverse personal discourses. Sharing and reviewing vignettes helped explicate the tacit and temporal experience of how meaning was constructed within each context of review. This insight into personal storytelling is fundamental to acknowledging and understanding personhood in the context of dementia. Further, though these findings were generated in the context of working with people with dementia, they may be translatable to other archival contexts and working with participants in research.

### 7.3.3 Sharing personal stories and temporality

Temporality is an existential and embodied experience that cannot be reduced to “textual and linear metaphors...Experience is different from words and symbols about those experiences. Words are always poor representations of the temporal and evocative lifeworld.”<sup>482</sup> Personal stories reflected only some of each individual’s values and beliefs as underlying assumptions and worldview. As already claimed in this thesis, the experience of storytelling is a *process* through which human beings

make sense of intentional action organized in time (Bruner, 1990; Ricoeur, 1983/1984), they are ideally suited for making sense of one’s own life in time (McAdams, 1993; Polkinghorne, 1988). Identity, therefore, may itself be viewed as an internalized and evolving story, a way of telling the self, to the self and others, through a story or set of stories complete with settings, scenes, characters, plots, and themes.<sup>483</sup>

Autobiographical stories helped interpret personal experiences.<sup>484</sup> The stories told in this research were not only “illness narratives” as described by Couser and Mairs.<sup>485</sup> Stories were told about their whole of life experience: past, present and future. Participants made sense of the worlds they had inhabited in a continuum of time. Time and temporality are unique and embodied experiences influenced by personal and cultural orientations.<sup>486</sup>

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<sup>482</sup> D. L. Altheide and J. M. Johnson, “Reflections on Interpretive Adequacy in Qualitative Research,” in *The SAGE Handbook of Qualitative Research*, ed. N. K. Denzin and Y. S. Lincoln (Thousand Oaks, CA: SAGE Publications, 2011), 590.

<sup>483</sup> J. S. Bruner, *Acts of Meaning* (Cambridge, MA: Harvard University Press, 1990); P. Ricoeur, *Time and Narrative*, trans. K. McLaughlin and D. Pellauer (Chicago, IL: University of Chicago Press, 1984); D. P. McAdams, *The Stories We Live by: Personal Myths and the Making of the Self* (New York: Guilford Press, 1993); D. Polkinghorne, *Narrative Knowing and the Human Sciences*, SUNY Series in Philosophy of the Social Sciences (Albany, NY: State University of New York Press, 1988) as cited in D. P. McAdams et al., “Stories of Commitment: The Psychosocial Construction of Generative Lives,” *Journal of Personality and Social Psychology* 72, no. 3 (1997): 678.

<sup>484</sup> A. D. Basting, “Looking Back from Loss: Views of the Self in Alzheimer’s Disease,” *Journal of Aging Studies*, special issue “Fashioning Age: Cultural Narratives of Later Life”, 17, no. 1 (February 2003): 87–99, doi:10.1016/S0890-4065(02)00092-0.

<sup>485</sup> G. T. Couser and N. Mairs, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison, WI: University of Wisconsin Press, 1997).

<sup>486</sup> W. L. Randall and R. Josselson, *The Stories We Are: An Essay on Self-Creation*. 2nd ed. (Toronto, ON: University of Toronto Press, 2014).

The terms “narratives and stories are sometimes used interchangeably in social research”.<sup>487</sup> I have intentionally adopted the term stories, throughout this thesis, in preference to narrative. The small stories recorded as person-centred records in this research were fragments of connected events.<sup>488</sup> The connections were not necessarily in a linear sense but rather in relation to associated meanings. Frank explains that in many discourses narrative “implies a sequence of events connected to each other through time.” These small stories were not always connected in a narrative sequence nor were they what Frank refers to as “chaos narratives” or an “anti-narrative of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself.” Frank explains that chaos stories “cannot be told”. He uses an example of research by Charmaz to demonstrate how this type of story can be “identified and a story reconstructed”. In this example the story has no narrative sequence, only an incessant present with no memorable past and no future worth anticipating.”<sup>489</sup>

From a social constructionist perspective, the storytelling was constructed through social interaction and reflected certain key characteristics. Narratives and stories were connected in relation to the meaning and value accorded in the storytelling context. Hence storytelling was not a linear process. There was an economy of choice in representing events by deciding which stories were told in order to communicate the inherent significance to a conclusion. Telling these stories in relationship to each other was a way of explaining identity, causal connections and the temporal constraints of these narratives. Participants in this research were consciously telling stories from the past as well as in the present. There was an awareness of time and place within these small stories. As explained in Chapter 4 these stories were relatively stable over time though decisions about how they were told or to whom were dependent on changing contexts.<sup>490</sup>

Telling stories and co-creating records were the activities that elicited the social construction of shared events that were uniquely experienced by those who participated. Co-creating personal records was the convergence of people experiencing contexts. As described in Chapter 1 Section 6.3 and Chapter 5 Section 4.4 of this thesis the experiential is temporal.<sup>491</sup> “Time is inherent in [his] bodily commitment and engagement in this situation, with its valences and tasks. Lived time is the movement of life itself.”<sup>492</sup> We experience our being in and through time. Though temporality is not explicitly mentioned in the drawing of the Experiential Model of the Person-Centred Record, it is embodied in those human experiences to which the concepts in the model refer. The term embodiment, as used within the model,

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<sup>487</sup> I. Goodson and S. Gill, *Narrative Pedagogy: Life History and Learning* (New York: Peter Lang, 2011), 4, [https://books.google.com.au/books?id=NJU2\\_nAihEC](https://books.google.com.au/books?id=NJU2_nAihEC).

<sup>488</sup> Lyotard’s concept of small stories as ‘petit recits’ influences the discussion in Upward and McKemmish, “In Search of the Lost Tiger, by Way of Sainte-Beuve: Re-Constructing the Possibilities in ‘Evidence of Me’.” [Response to Harris, Verne. On the Back of a Tiger: Deconstructive Possibilities in ‘Evidence of Me’.”]

<sup>489</sup> A. W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics*, 2nd ed. (Chicago, IL: University of Chicago Press, 2013), 98–99.

<sup>490</sup> These characteristics I reported were consistent with Gergen as described in Goodson and Gill, *Narrative Pedagogy: Life History and Learning*, 4–5.

<sup>491</sup> The term temporal is being discussed here in the psychological sense.

<sup>492</sup> Fuch (2010) as cited in Stanghellini and Rosfort, *Emotions and Personhood: Exploring Fragility - Making Sense of Vulnerability*, 245.

always refers to the *personal experience* and meaning associated with the storytelling process and participant perspectives when reviewing stories in the form of a vignettes and as a records.

### 7.3.4 Making meaning and representing perspectives

This section is a discussion of how I addressed the ‘messiness of the empirical world’ in order to tell coherent analytic stories, those ‘parts’ of our work which are omitted due to the differences, contradictions and incoherencies in the data.<sup>493</sup> I made decisions in this research which impacted on how perspectives were represented, as part of a reflexive review process with participants. Representing perspectives and meaning accentuated the creative tension between the documentary process which I have previously referred to as evidencing and what Harris describes as the ‘archival sliver’. Evidencing, as the gerund implies, is an activity that is occurring, ongoing and not yet complete. “Experience is never unmediated”. It is shaped and by one’s experience, personal and professional.<sup>494</sup> As Harris discloses his complicity in the recordkeeping process I too reflect on how I was not an objective observer in the context when co-creating the vignettes in this research.

For Harris “the documentary record provides just a sliver of a window into the event”. He questions just how much the record is capable of representing what in reality are multiple possible perspectives of an event. The ‘act of recording’ in effect feeds into social memory in a way that can both reflect and distort.<sup>495</sup> The work of the archivist is, in Harris’s eye, always subjected to the call of and for justice in archives in all contexts.<sup>496</sup> Harris’s ‘sliver’, in whatever we perceive to be ‘*actual*’, will only ever be ‘a part’ of another ‘sliver’. The postmodern influence, be it present or already past, “has not so much been the relativizing of truth (to the point even of making it irrelevant) but rather the multiplication of perspective”.<sup>497</sup> “Archival researchers and archivists are exploring a multiplication of perspectives.”<sup>498</sup>

The process of analysing the open interviews and creating the vignettes in this research revealed many perspectives and highlighted some of the challenges of recording meaning such as states of being which are many, mutable and changing. Though the stories documented in the vignettes were all based around life events, these events were associated with embodied states of being, within the context of the stories as told; the context of the telling as well as the personal recording. Meaning and states of being, such as how people felt about their storytelling and personal recordkeeping, were influenced by the content in the situated context. Content, context and meaning were all interdependent, and influenced decision-making when co-creating personal records.

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<sup>493</sup> Clarke, “Situational Analyses,” 15.

<sup>494</sup> Harris, “The Archival Sliver,” 63.

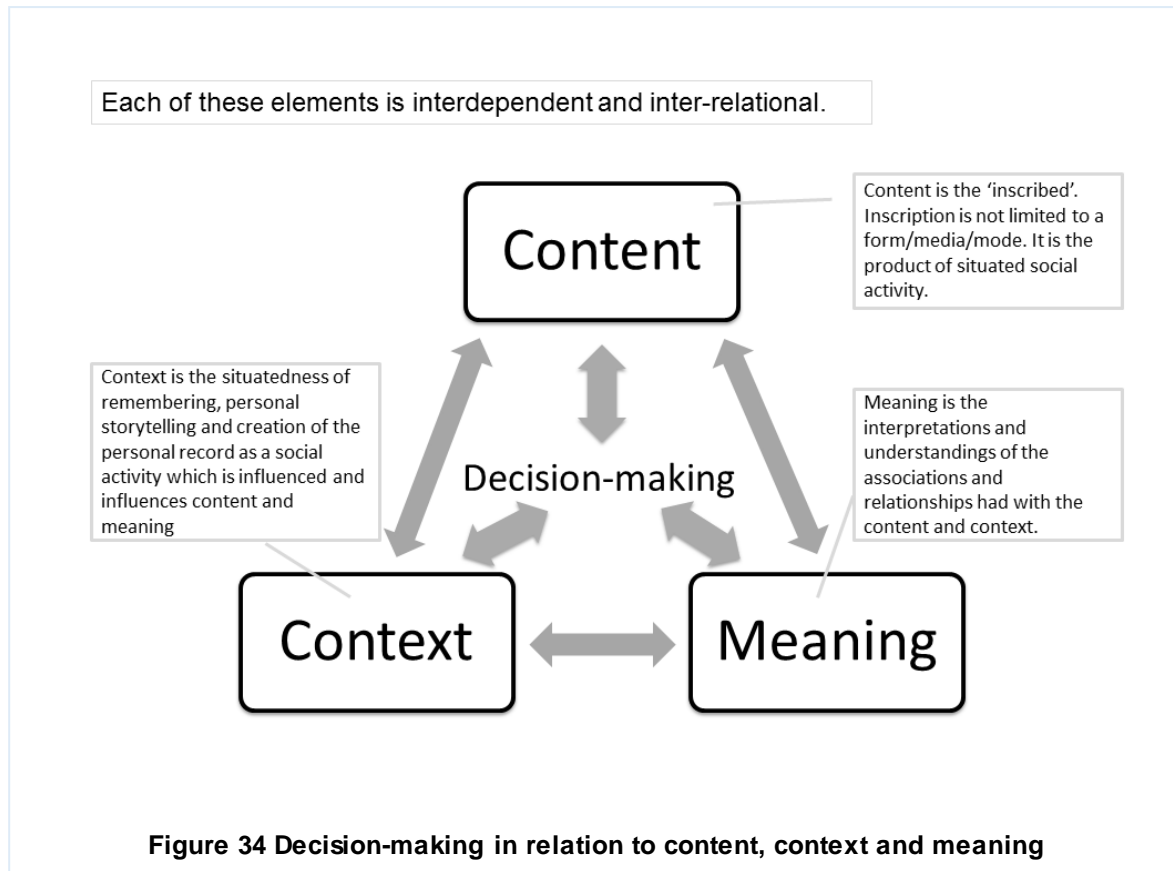
<sup>495</sup> *Ibid.*, 64.

<sup>496</sup> Verne Harris uses the metaphor of ‘the archival sliver’ when he writes about his personal and professional experience on “archives” in the “context of South Africa’s transition from apartheid to democracy”. Harris, “The Archival Sliver.”

<sup>497</sup> Niek van Sas as cited in Ketelaar, “Tacit Narratives,” 132.

<sup>498</sup> *Ibid.*

Reflecting on Harris's archival sliver, in which the record provides only partial perspectives of the context of creation,<sup>499</sup> the work that I undertook, and the findings from the research, highlighted how the elements of content, context and meaning were interdependent and inter-relational. Decision-making needs to take into account the situated contexts within which the records are being co-created. These contexts of activity have the capacity to influence the way content and meaning of records are constructed. The inscribed content is also able to influence the way meaning is constructed and represents perspectives. Figure 34 depicts the process of decision-making as being underpinned by interdependent and inter-relational elements of content, context and meaning.



Making meaning explicit is a reflexive process and not always conscious. Meaning was subjective and personal as was the response to the object of that meaning. Participants had their own vocabulary and ways of expressing meaning. The vignettes were a placeholder in time and place and a tool for analysing meaning of life events. The way each person spoke, about their stories, emotions, feelings or affect, revealed diversity and complex descriptors of meaning referencing language and embodied experience. Some of these descriptors were about how the person would describe their own characteristics. Some of the descriptors were embodied in *how* the person experienced the world.

There were a range of story types or processes evident in the findings of this research, and the literature supports definitions of narrative as a personal process. For example *accounts* are

<sup>499</sup> Harris, "The Archival Sliver."

when “we interpret and explain the action-sequence we perform and the acts we thereby accomplish...an account is not to be interpreted as an introspective causal explanation...[they] are generated by ordinary people in the ordinary course of social action...accounting seems to involve the performance of two main tasks: the explication of action and the justification of action.”<sup>500</sup> These stories were examples of the person’s personality in terms of their learned resources and their engagement in the *here and now*; they were adaptive and experiential.<sup>501</sup> These events and states were temporal though they were not necessarily chronological.

These findings highlight the complexity of inscribing this embodied and experiential meaning. For social constructionist Gergen “Descriptions remain static but actions are ever shifting”<sup>502</sup> There can be much disjunct between words and the world.<sup>503</sup> When taking photos of the participants, for the vignettes, I captured states of being which are not always represented or expressed through words or text. These states were sometimes represented through the audio-recordings of the interviews but they only came together through the social encounters which were relational and constructed over a period of time. There was more than one state of being or meaning associated with an event and the state(s) could change over time. These states were responses to evolving relationships with the stories and vignettes as records. They were not fixed but rather part of a continuum of states of being in relation to meaning.

Consistent with Stanghellini and Rosfort, emotion was a salient way of knowing the world. I believe there are inherent risks in describing records in a way that fixes the participant’s response in a single moment in time.<sup>504</sup> Alfred Eisenstaedt said, “all the photographer has to do is find and catch the story-telling moment.”<sup>505</sup> It is a salient point that the process of documenting someone’s stories through interview activities results in the collection of “natural material”.<sup>506</sup> In the case of this research project, natural material consisted of mixed media including recorded voices, copies of existing photographs, and new photographs captured in the course of the interviews. Grierson was talking about the emerging field of documentary using film when he explained the passing from “descriptions of natural material, to arrangements, rearrangements, and creative shapings of it”.<sup>507</sup>

The products of the interviews, in the form of vignettes and life books, in many ways reflected this description of the documentary process. The products of research were not reality or a mirror, nor did they represent the process of co-creation. Co-creating vignettes was part of

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<sup>500</sup> R. Harré, *Social Being* (Oxford: Blackwell, 1993), 134.

<sup>501</sup> Harré, “The Explanation of Social Behaviour.”

<sup>502</sup> K. J. Gergen, *Realities and Relationships: Soundings in Social Construction* (Cambridge, MA: Harvard University Press, 2009), 31. Kindle Edition.

<sup>503</sup> Ibid., Kindle Location 483.

<sup>504</sup> Stanghellini and Rosfort, *Emotions and Personhood: Exploring Fragility – Making Sense of Vulnerability*, 10.

<sup>505</sup> A. Eisenstaedt, “Alfred Eisenstaedt Quotations and Tips about Photography,” *PhotoQuotes.com: Quotations from the World of Photography*, accessed December 12, 2012, <http://www.photoquotes.com/printableshowquotes.aspx?ID=93>.

<sup>506</sup> J. Corner, *The Art of Record: A Critical Introduction to Documentary* (Manchester: Manchester University Press, 1996), 12.

<sup>507</sup> J. Grierson, *Grierson on Documentary*, ed. F. Hardy, rev. ed. (Berkeley, CA: Faber, 1966), 146, <http://books.google.com.au/books?id=fgQnAQAAIAAJ>.

progressively evidencing ‘slivers’, as described by Harris, of participant experience and through records. There were many slivers; they were always only part of the whole experience and susceptible to change. Upward, McKemmish and Reed described this phenomenon, through records continuum theory, as a flicker in which the record is being continuously renewed, as a re-commencement in each moment in time.<sup>508</sup> The findings of this research illuminate the challenges of trying to represent, in records and their descriptions, knowledge, human experiences and meaning which are constantly being re-constructed.

### 7.3.5 Postmodern challenges of recording memory and stories of self

The discussion in the previous section, characterised records and the processes for their co-creation as representing fragments of our realities and identity. These postmodern concepts were consistent with records continuum thinking, as described in Chapter 2. The embodied experience and vignettes as representations of self create challenges in how this information can be recorded and shared.

Identity is constructed and re-constructed through relationships, both social and material. So too are personal stories and the response to those stories ongoing, shifting and changing. The reactions of others are very important in the construction of identity. Undertaking this research required that I explore how co-creating person-centred records made time and place to understand interpersonal relationships and their impact on records; as a process which extends beyond the record as a representation. This is consistent with social constructionist Gergen’s position that identity is highly situated and changing in relation to contexts.<sup>509</sup> The findings of this research with respect to the processual nature of co-creating person-centred records is also consistent with continuum theorists’ understandings of the nature of records as constantly evolving in their meanings, through their relationships to people and situated in multiple changing contexts (discussed in Chapter 2).<sup>510</sup>

Through a postmodernist lens, personhood in this research was socially constructed through relationships with people as well as with the products of human activity, of which records were an outcome. The term socially constructed is used in common language but it is also an important body of theory which emanates from the divergence of modern and postmodern discourses.

For modernists, the world simply is “out there” available for observation. Within the texts of postmodernism, however, there are no grounds for such a presumption. There is no means of declaring that the world is either “out there” or reflected objectively by an “in here”. To speak of “the world” or “mind” at all, requires language. Such words as “matter” and “mental process” are not mirrors of the “material world,” and “causal relations” is not to describe

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<sup>508</sup> F. H. Upward, S. McKemmish, and B. Reed, “Counterpoint Archivists and Changing Social and Information Spaces: A Continuum Approach to Recordkeeping and Archiving in Online Cultures,” *Archivaria* 72, Fall (2011): 197–237.

<sup>509</sup> Gergen, *An Invitation to Social Construction*, 1999, 80.

<sup>510</sup> McKemmish, “Evidence of Me. . .”; Ketelaar, “Tacit Narratives”; Harris, “Claiming Less, Delivering More”; Harris, “On the Back of a Tiger: Deconstructive Possibilities in ‘Evidence of Me.’”



accurately what there is, but to participant in a textual genre – to draw from the immense repository of intelligibilities that constitute a particular cultural tradition.<sup>511</sup>

As an exemplar of alternative approaches to personhood in psychology Kitwood draws on the work of social psychologist Harré (with a background of philosophy/social psychology) who describes personhood as a paradigm. His “central assumption is that each person is a meaning-maker and an originating source of action.”<sup>512</sup> These lenses guided the research, in understanding the unique perspectives of each individual participant in the research, regarding their sense of self and life as a whole not only in terms of their records. These were their situated contexts. Personal realities were many, subjective and changing as were their relationships to records which already existed and that we co-created. The co-creation of records was more than a set of processes but rather embedded in practice. As researchers we should be seeking the perspectives of participants, “beyond its recognizably constituted forms”, challenging our ways of knowing voice and meaning.<sup>513</sup>

As with memory “the ordinary course of life rarely generates objective records. Even when a record happens to exist...it is often susceptible to more than one interpretation.”<sup>514</sup> A memory is something which happens in the present. Can I say I had a memory that no longer exists? I *have* a memory. I will remember this or they will be great memories. A memory is always contextualised in the present. It is a perspective on events of the past or even the conscious noting of what is occurring in the here and now – recording it to memory for the future. But each time we remember it is a (re)membering in the context of that moment in time and place. The memories as records have no age as such. They may have an identifiable moment of birth in the event that took place. Memory is not an objective activity or thought. Memories have many ages and iterations and the way we feel at the time will be reflected in the way we feel in that memory.

Albright coined the phrase “the brokenness of memory” as a gap when the remembered self is incomplete and full of empty spaces which are freed rather than bound by memory.<sup>515</sup> The human self is not the unified and coherent but “mutable; shifting, shifting, shifting, growing unrecognizable from moment to moment”.<sup>516</sup> Plurality and ambiguity are part of the process of continuously becoming who we were, are and will be.

Memory is not just something which occurs on an intellectual level. Memory is something which happens with all our body and our mind. Within memory is embodied our identities,

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<sup>511</sup> Gergen, “Psychological Science in a Postmodern Context,” 61.

<sup>512</sup> Harré, “The Explanation of Social Behaviour,” as cited in Kitwood, *Dementia Reconsidered: The Person Comes First*, 15.

<sup>513</sup> L. A. Mazzei, “An Impossibly Full Voice,” in *Voice in Qualitative Inquiry: Challenging Conventional, Interpretive, and Critical Conceptions in Qualitative Research*, ed. A. Y. Jackson and L. A. Mazzei (London: Routledge, 2009), 47. Kindle Edition.

<sup>514</sup> Neisser draws on previous works in relation to other theories of remembering. Neisser, “Self-Narratives: True and False,” 1–2.

<sup>515</sup> D. Albright, “Literary and Psychological Models of Self,” in *The Remembering Self: Construction and Accuracy in the Self-Narrative*, ed. U. Neisser and R. Fivush (Cambridge: Cambridge University Press, 1994), 22.

<sup>516</sup> *Ibid.*, 30.

our feelings both emotional and physical, as well as the narratives of events. We can attempt to separate out these affects but in doing so we also lose the context and the impact of the perspective being told.

Neisser describes complexity in the way we remember, know and experience the world.

People are perceivers as well as rememberers. At all times we can directly see (and hear and feel) where we are and what we are doing; even whether we are socially engaged (Neisser, 1990 3b). However accurately or inaccurately we may recall or reconstruct the past, *this/ hear/ now* is the present state of affairs for us. On the other hand, perception and the present are not always the individual's most important concern. Wherever we happen to be here and now, we can still be caught up in some compelling memory from long ago and far away. Like it or not, then, self-knowledge is intrinsically multimodal. It cannot be reduced to any single source of information.<sup>517</sup>

Remembering and the construction of meaning “are bound together by the emotional life of individuals interconnected with the lives of others.”<sup>518</sup> As with memory “the ordinary course of life rarely generates objective records. Even when a record happens to exist (e.g., a tape recording; cf. Neisser, 1981), it is often susceptible to more than one interpretation.”<sup>519</sup>

According to Edwards and Potter, reality is not so much something against which memories can be checked as something established by those memories themselves. “Everyday conversational remembering often has this as its primary concern—the attempt to construct an acceptable, agreed, or communicatively successful version of what really happened.”<sup>520</sup> The ‘*truth*’ about memory and how we remember is controversial even among those experts who spend their whole careers studying these processes. In the postmodern world autobiographical memory is always a reconstructed version of what was remembered before and may be reconstructed tomorrow.<sup>521</sup>

As illustrated in this thesis, memories were contextualised in the present. The social context was important.<sup>522</sup> “(Autobiographical) memories are the phenomenal reality of self as existing in the present and extending over time past and into the expected future.”<sup>523</sup> It is a perspective on events of the past or even the conscious noting of what is occurring in the here and now – recording it to memory for the future. But each time we remember it is a (re)membering in the context of that moment in time and place. The memories as records

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<sup>517</sup> Neisser, “Self-Narratives: True and False,” 10.

<sup>518</sup> C. R. Barclay, “Composing Protoselves Through Improvisation,” in *The Remembering Self: Construction and Accuracy in the Self-Narrative*, ed. U. Neisser and R. Fivush (Cambridge: Cambridge University Press, 1994), 60.

<sup>519</sup> Neisser, “Self-Narratives: True and False,” 2.

<sup>520</sup> Neissen draws on previous works in relation to other theories of remembering. *Ibid.*, 1–2.

<sup>521</sup> *Ibid.*, 8.

<sup>522</sup> M. Halbwachs and L. A. Coser, *On Collective Memory* (Chicago, IL: University of Chicago Press, 1992); K. J. Gergen, “Mind, Text and Society: Self-Memory in Social Context,” in *The Remembering Self: Construction and Accuracy in the Self-Narrative*, ed. U. Neisser and R. Fivush (Cambridge: Cambridge University Press, 1994), 78–104.

<sup>523</sup> Gergen, “Mind, Text and Society: Self-Memory in Social Context,” 60.

have no age as such. They may have an identifiable moment of birth in the event that took place. They have many ages and iterations and the way we feel at the time will be reflected in the way we feel in that memory.

Memory is not just something which occurs at a cognitive level. Memory is something which happens as an integrated activity with our whole self: body and mind. Within memory is embodied our identities, our feelings both emotional and physical, as well as the narratives of events. Constructing records of memories and stories as narrative events in this research raised awareness of how personal stories are connected to context. Recording and describing content, context and meaning is both difficult and fragile.

### **7.3.6 In summary**

Section 7.3 provided a discussion in which I evaluated the Experiential Model of the Person-Centred Record as a social constructionist grounded theory. I highlighted the importance of a person-centred approach as reflexive and ethical practice for working in research, and the impact of this when recording personal stories, memory and meaning. This discussion expanded on the postmodern paradigms and principles through which the fourth research question will be addressed in the following section.

## **7.4 *Ethics and Reflexive Practice: Being the Ethical Archivist and Researcher***

The understandings of interpersonal processes explored so far, place the roles and responsibilities of archivist and archival researcher under scrutiny, particularly in working with people with dementia and their records. Decision-making in emergent personal archival spaces becomes a moral act. Ethics and reflexivity become ways of knowing and doing in relation to the perspectives of the people with dementia. The person-centred record is a particular type of record informed by ethical and reflexive practice, co-created to support memory, identity and personhood. This thesis is an exemplar of how the role of archivist can be extended into new and applied problem spaces. The responses to the research questions are extensive descriptions of co-creating records in this archival research. Especially when working in new contexts, as is the case in this archival research, the research questions are being asked with regard to what has not yet been studied.

In Section 7.4, I discuss the findings of this research with respect to postmodern challenges of decision-making in new and emergent research contexts. This discussion focuses on responding to the fourth research question: How do we achieve a rich understanding of the ethical issues and processes involved in this kind of record co-creation? The archival researcher when co-creating records in new problem spaces is required to make explicit the reflexive processes for decision-making and the theoretical influences through which these decisions were made. Postmodern thinking has implications for how people and their records were co-created and studied. I have made claims in this research based on particular worldviews and ways of engaging with the world.

All inquiry is inevitably perspectival, and its results inherently partial and interested. All knowledge claims are necessarily embedded within a specific way of engaging in the world. It follows that objectivity cannot be the elimination of all cognitive and moral presuppositions; far from opening the eyes of potential cognizers such an elimination would in fact render them blind, unable to see anything at all.<sup>524</sup>

It is significant in drawing this thesis to conclusion that I again reflect on the dimensions of applied research described in Chapter 3 Section 6. The model was identified as part of a reflexive process to understand the complexity and dimensions which constituted the situated research contexts. “Reflexivity has a more central role in helping people navigate their way through the world”.<sup>525</sup> Ethics was as an ongoing process in the situated contexts of people with dementia, through underpinning theories, practice and the products of the research. Fundamental to creating new knowledge was decision-making informed by the philosophical and theoretical influences in this research. The implications of the sensitive research contexts and postmodern thinking was expressed through reflexive researcher practice and the co-creation of records as product of interpersonal processes. The ethical dimensions of research are demanding more attention as there is increasing awareness of how perceived moral obligations to the researched are being challenged.<sup>526</sup>

Duff and Harris highlight how postmodernism is challenging assumptions regarding the role of the archivist in relationship to the life of a record. Archival interventions are not “outside the constructions of meaning and the exercise of power”.<sup>527</sup> They posed key questions about the archival roles and responsibilities in existing contexts particularly regarding their ethical and decision-making involvement in record creation and description.<sup>528</sup>

On one hand reflexivity is the recognition of the ways that the self always mediates the social world; Researchers know only about the world through our own experience of it. On the other hand, reflexivity is also a constant awareness of how the social conditions of research affect the production of knowledge.<sup>529</sup>

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<sup>524</sup> B. Fay, *Contemporary Philosophy of Social Science: A Multicultural Approach* (Malden, MA: Wiley, 1996), 216.

<sup>525</sup> M. Dyke, “An Enabling Framework for Reflexive Learning: Experiential Learning and Reflexivity in Contemporary Modernity,” *International Journal of Lifelong Education* 28, no. 3 (June 2009): 290.

<sup>526</sup> M. Churton and A. Brown, *Theory and Method*, 2nd ed. (Basingstoke, Hampshire: Palgrave Macmillan, 2010), 345.

<sup>527</sup> W. M. Duff and V. Harris, “Stories and Names: Archival Description as Narrating Records and Constructing Meanings,” *Archival Science* 2 (2002): 263–85. As Duff and Harris explain, this thinking is particularly evident in the work of Terry Cook who drew on discourse from both within and outside of archival discourse.

<sup>528</sup> The questions were listed as: “What do archivists mean by the terms “text” and “context”? Is the context to the record finite in its reach? Does the making of a record, ultimately, have a beginning and an ending? Do archivists participate actively in the construction of record’s meanings and its significance? Is the notion of the archivist maintaining an exteriority from both processes of records creation and broader societal processes a chimera? Do power relations, with their myriad of privilegings and exclusions, find expression in archival intervention (or non-intervention)? Does the archivist have a moral obligation to engage the marginalized and excluded voices in records? Is the archivist a storyteller? How do the contingencies of language and narrative shape the work of archival description? Is archival description simply a form of narration? Should archivists disclose their complicity in the processes of record making? And, in light of all the preceding questions can there be a meaningful standardization of archival description?” Ibid., 265.

<sup>529</sup> Pascale, *Cartographies of Knowledge: Exploring Qualitative Epistemologies*, 71.

Within and between disciplines the norms of research ethics may vary considerably. Research is in the throes of theory and practice ranging from positivist views around truth and objectivity, to the interpretivist questioning of what it all means, critical theory views about questioning power and enculturation in social processes. It is important to consider how these norms influence research as the production of knowledge and its relationship to people in a world context particularly as scientific discourses which have privileged “the practical work of scientific research necessarily reproduces culturally shared assumptions about how the world exists and how it works.”<sup>530</sup>

Social constructionism is the process of interpretation, and analytic induction is the process of formalization in this analysis. While analytic induction shapes what can be understood as an exemplar, indeed what is understood as evidence, in the analysis itself, the process of analytic induction through which the patterns and exemplars were created is not visible. The power and influence of analytic induction as a methodological framework is never at the surface of analyses – it is never accountable as a productive force of this analysis...social constructionism is visible as the interpretive process.<sup>531</sup>

Reflexivity was fundamental to researcher practice, throughout the course of the research and in representing how this new knowledge was created. A criticism of representing social constructionist processes within social research is that the reflexive processes, on which interpretation and findings are so dependent, are often omitted when reporting the research. “Social research ethics are not just a set of rules to protect the people researchers study... learning to be a scholar [is] a different process of learning to be accountable to a different set of ethics than those used in daily life.”<sup>532</sup> Attention needs to be paid to the ethical dimensions of research and perceived moral obligations to the researched.<sup>533</sup>

#### **7.4.1 Ethical wayfinding in the situated context and co-creating records**

A key characteristic of methodological wayfinding, as described in Chapter 3 Section 3.1, was that all wayfinding processes were framed by ethical practice and dependent on understanding the meaning of situated contexts. As demonstrated throughout this thesis, qualitative research is both valued and inherently challenging in its capacity to adapt to situated contexts as they unfold. The ethical implications of this uncertainty is most evident in how we make decisions. Particularly in postmodern times, the researcher, must contemplate those moments which cannot be imagined. Guillemin and Gillam argue that “procedural ethics cannot in itself provide all that is needed for dealing with ethically important moments in qualitative research.” Reflexivity should be considered a “conceptual tool for understanding both the nature of ethics in qualitative research and how ethical practice in research can be achieved.”

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<sup>530</sup> Ibid., 15.

<sup>531</sup> Ibid., 58.

<sup>532</sup> Ibid. 7.

<sup>533</sup> Churton and Brown, *Theory and Method*, 345.

Reflexivity in research is not a single or universal entity but a process – an active ongoing process that saturates every stage of the research.<sup>534</sup>

The findings of this research in relation to ethical wayfinding, as a process for decision-making in archival research, further answer the second part of the research aim; that is, exploring how second generation grounded theory contributes to archival theory and possible implications for practice. This second generation grounded theory was based on reflexive practices in the situated contexts of participants with dementia. The emphasis of this grounded theorising when working with people, in relation to their data and co-creating records focused the research on the peoples' experiences and perspectives as they evolved. Methodological and ethical wayfinding as described in this research, are about developing practices in the situated context; orientating the researcher and archivist to concurrently consider the many dimensions which influence decision-making in this type of archival work.

Decision-making within this applied archival research involved processes for thoughtful and systematic analysis of the data as they were generated as well as collected. Decision-making was informed through developing theoretical sensitivity; that is, through ongoing learning and understanding the implications of values and beliefs on practice. In the context of this research, I was challenged to consider the ethical implications of making decisions about how and what records were created, both with other people and on their behalf.

Getting to know a person in a constructed research context took both skills and sensibility. I learned to listen and hear people's stories through practice by paying attention to theory as well as outcomes. Identifying person-centred stories was often about finding the extraordinary in the ordinary. I discovered how each of the participants in their situated contexts is unique and influenced by social forces. As I got to know the person I was interviewing, I realised how much I could learn from these personal stories. I like to think of and describe these stories as faithful, if sometimes understated, in just how they related to the personal narrative and personhood. These stories bubbled up through our conversations. Through their telling they wove themselves into the fabric of my own experience and memory. Knowing someone means becoming familiar with their stories. If each telling of a story is a socially constructed and recordkeeping event, then it is related to the situated context of that telling.

Being a mindful researcher meant making decisions, considering ethical processes and duty of care, with participants as well as the products of research. Science is defined by Forge as a "body of ideas which affects us and the way we live." He believes that whether it is pure or applied science that is being undertaken, responsibility is embodied in the work. The difference begins and ends with the context rather than the nature of the work and their relationship to 'an end' is more similar than not and all scientists have responsibility for the outcomes of their work.<sup>535</sup>

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<sup>534</sup> M. Guillemin and L. Gillam, "Ethics, Reflexivity, and 'Ethically Important Moments' in Research," *Qualitative Inquiry* 10, no. 2 (April 1, 2004): 262–63, doi:10.1177/1077800403262360.

<sup>535</sup> J. Forge, *The Responsible Scientist: A Philosophical Inquiry* (Pittsburgh, PA: University of Pittsburgh Press, 2008), 2.

This set of unique attributes includes the repertoire of personality and personal resources such as events and states which are developed by an individual throughout their lifetime. These resources are experienced as events and states of being.<sup>536</sup>

The experiential and embodied dimensions of the studied phenomenon are complex. Emotions and the embodied experience underpin empathy as an intersubjective process. Empathy requires a “true, or authentic, emotional understanding to occur, two individuals must produce a common field of shared experience that they can enter into, each drawing”.<sup>537</sup> Lived emotions are embodied and it is these which enable feelings to be shared with others.<sup>538</sup>

Within and between disciplines the norms of research ethics may vary considerably. It is important to consider how these norms influence research as the production of knowledge, and in its relationship to people. The practical work of scientific research necessarily reproduces culturally shared assumptions about how the world exists and how it works.”<sup>539</sup>

#### 7.4.2 Theory: Research ethics in postmodern times

In the case of this thesis, the personal and intimate nature of shared information is even more salient. The co-creation of person-centred records was both the processes involved in production, and the product as the outcome of those processes; they was contingent on the ability of the recordkeeping process to reflect personhood and be person-centred. And yet, the co-creation of person-centred records is but one reality among many of what may seem, conflicting perspectives in the PhD thesis process. Notions of reality are contested across disciplines, theory, amongst people and in the evidence created. There are many ways to know the world and “multiple realities”.<sup>540</sup> Congruency in applied research is about understanding perspectives in relation to each other rather than as conflicting views.

The philosophical basis of research ethics is ultimately premised on the fact that our research requires that we locate people who, to serve our research objectives, are willing to share information about themselves, information that is often of a highly personal and intimate nature.”<sup>541</sup>

The obligations of the researcher are complex and further complicated by the many perspectives. So, how is it possible to address notions of truth, through a postmodern lens, to produce new knowledge which is also ethical? Research ethics is a branch of “applied (or practical) ethics which studies the ethical problems, dilemmas, and issues that arise in the

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<sup>536</sup> Harré, “The Explanation of Social Behaviour.”

<sup>537</sup> N. K. Denzin, *On Understanding Emotion* (San Francisco: University Microfilms, 1994), 146. Kindle Edition.

<sup>538</sup> Ibid.

<sup>539</sup> Pascale, *Cartographies of Knowledge: Exploring Qualitative Epistemologies*, 15.

<sup>540</sup> J. K. Smith, *The Nature of Social and Educational Inquiry: Empiricism Versus Interpretation* (Norwood, NJ: Ablex, 1989).

<sup>541</sup> B. E. Haverkamp, “Ethical Perspectives on Qualitative Research in Applied Psychology,” *Journal of Counseling Psychology* 52, no. 2 (2005): 149.

conduct of research.”<sup>542</sup> Ethics in research has been described by scholars as being “concerned with...questions about duty, honour, integrity, virtue, justice, and the good life,”<sup>543</sup> and about being responsible, a good citizen, objective, honest, accurate, and efficient.<sup>544</sup>

In this postmodern world replete with more choices than ever before we, as researchers, are held accountable not only to the production of knowledge but how that knowledge is produced. Ethics in postmodern times is less about being right or wrong and more about the process of making choices from other possible choices. Decision-making requires assessing, measuring and evaluation of the possible actions and this raises questions regarding: “the criteria of evaluation and dimensions of measurement” when the same action can diverge into ‘right in one sense and wrong in another’ depending on the contexts.<sup>545</sup> The postmodern theorist prefers to “abandon overarching paradigms and theoretical methodological metasystems” in order to position themselves within complexity by studying in detail the smaller, even fragmented parcels of knowledge in order to learn about the “the multiple levels of social reality”.<sup>546</sup> Our actions

may have profound, far-reaching and long-lasting consequences, which we can neither see directly nor predict with precision. Between the deeds and their outcomes there is a huge distance – both in time and in space – which we cannot fathom using our innate, ordinary powers of perception – and so we can hardly measure the quality of our actions by a full inventory of their effects.<sup>547</sup>

The postmodern world is at the core of a paradigm shift for archival science moving from a fixed, nature of records to dynamic virtual concepts.<sup>548</sup> In life we accumulate, as well as consciously collect, the functional, the things of meaning, the memories themselves or what might be considered mnemonic devices for remembering. As McKemmish explains “Recordkeeping is a ‘kind of witnessing’. On a personal level it is a way of evidencing and memorialising our lives – our identity, our ‘place’ in the world.” Individuals accumulate ‘personal records’ over time as part of an archiving process. There are ‘outwards and inwards files’. It is both private and dependent on our external environments. It both shapes and is shaped by our inner and outer worlds.<sup>549</sup>

Cross-disciplinary approaches to understanding the significance of records and archives in the context of broader global challenges has led to what anthropologist Stoler describes as the ‘archival turn’. The archival turn is born out of the post-colonial understanding of the archive and recordkeeping in which archives are “not sites of knowledge retrieval but sites of

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<sup>542</sup> Shamoo and Resnik, *Responsible Conduct of Research*, 15.

<sup>543</sup> *Ibid.*, 13.

<sup>544</sup> Steneck, *ORI Introduction to the Responsible Conduct of Research*, xi.

<sup>545</sup> Z. Bauman, *Postmodern Ethics* (Malden, MA: Blackwell Publishing, 1993), 4–5.

<sup>546</sup> Borer, Silverman as cited in Borer and Fontana, “Postmodern Trends: Expanding the Horizons of Interviewing Practices and Epistemologies.”

<sup>547</sup> Giddens, *Modernity and Self-Identity: Self and Society in the Late Modern Age*, 3–4 as cited in Bauman, *Postmodern Ethics*, 17.

<sup>548</sup> Cook, “Archival Science and Postmodernism,” 4.

<sup>549</sup> McKemmish, “Evidence of Me...”



knowledge production.<sup>550</sup> Here archives are reimagined. Instead of being “inert sites of storage and conservation” they “are concerned with the legitimating social coordinates of epistemologies: how people imagine they know what they know and what institutions validate that knowledge, and how they do so”.<sup>551</sup>

The findings of this applied research is an exemplar of undertaking research through the ‘archival turn’; the archive is reconceptualised through theory and practice influenced by participatory epistemology which makes explicit the social and co-construction of knowledge (described in Chapter 2). The importance of exploring how epistemologies converge and contribute to the production of new knowledge is particularly salient in complex contexts such as understanding personhood and dementia. “Philosophical contributions are valuable, because they can help sharpen our thoughts about what we do as practitioners working in a variety of ways to help people with dementia.”<sup>552</sup>

Ethics and reflexivity when co-creating person-centred records in this research was firmly embedded in researcher practice; that is the ways in which I as the archivist and researcher worked with people as well as their records. Practice was guided by making explicit and translating into practice underlying postmodern theories of personhood and a participatory epistemology. I had to *know* each person and their unique and changing needs through developing relationships and safe contexts for knowing. Research ethics in postmodern times, is a process and principles for creating new options or choices for action in order to address situations we cannot yet imagine.

### 7.4.3 Ethical wayfinding: Record production is both tacit and explicit

Ethical wayfinding in this research was a practice of challenging assumptions to understand the perspectives of other people and their records in this research. Ethical wayfinding in the context of this archival research and practice meant acknowledging that the boundaries of the relationships and records were soft. These findings highlight the challenges of co-creating records where archival decision-making is not about being right or wrong; rather the archivist focuses on sensitive and ethical approaches to representing the perspectives of people and their records. There was no single interpretation or view of the person-centred records we co-created within a context, but rather many perspectives which could co-exist or be challenged in themselves. The archival multiverse described in Chapter 2, is a complex space in which archivists and archival researchers are working within new and emergent contexts, and developing new knowledges to support specific recordkeeping needs as they evolve.

The record could be described as a meme – “a cultural entity as a replicator”<sup>553</sup>, a mnemonic device, a trace as Derrida describes as the unfindable.<sup>554</sup> The record is the use of *technology* to make explicit a perspective. The record is an extension of self and a construction within a

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<sup>550</sup> Stoler, “Colonial Archives and the Arts of Governance,” 87.

<sup>551</sup> Ibid., 90.

<sup>552</sup> Hughes, Louw, and Sabat, *Dementia: Mind, Meaning, and the Person*, Preface.

<sup>553</sup> D. Taylor, *The Archive and the Repertoire: Cultural Memory and Performance in the Americas* (London: Duke University Press, 2003), 173.

<sup>554</sup> Derrida, *Archive Fever: A Freudian Impression*, 62.

person's environment. Describing the recording may be anything that communicates the relationship to context. It is not just in the text.

Stories go in circles. They don't go in straight lines. It helps if you listen in circles because there are stories inside and between stories, and finding your way through them is as easy and as hard as finding your way home. Part of finding is getting lost, and when you are lost you start to open up and listen.<sup>555</sup>

Personal stories and person-centred records of life are recursive in their complexity and difficult to pin down. They take you to unexpected places. Perspectives were profuse and as the participants and I interacted we all changed. We changed from moment to moment. We changed over the weeks we encountered. We kept changing as the after effect of sharing and experiencing stories continued to work its way into shared memories.

The singularity we each feel ourselves to be, is not an entity. Rather it is a site, a site from which a person perceives the world and a place from which to act. There are only persons.<sup>556</sup>

Personhood was ever shifting as was personal recordkeeping in evidencing a person. What was this tenuous relationship between the way an individual perceives themselves and how they feel they are perceived in a record? Personhood was not about defining one person as distinct from another. Rather, personhood was an interpersonal process of wayfinding; we were positioning and repositioning in relation to self, others and the records we co-created. Moghaddam and Harré describe positioning theory being "how people use words (and discourse of all types) to locate themselves and other...it is with words that we ascribe rights and claim them for ourselves and place duties on others."<sup>557</sup> "There are direct moral implications insofar as the way in which the rights and privileges of people with AD [Alzheimer's disease] can be abridged or respected, depending on the ways in which they are positioned."<sup>558</sup>

The theories of personhood discussed in this research, contributed to understanding personhood for people with dementia and in co-creating person-centred records. These knowledges highlighted the integral connection between the way people can know and express identity and meaning through co-creating records.

Decision-making was an ongoing process in all stages of the research by both me and the participant. Decisions were made regarding the telling, representing and sharing of stories and the vignettes were one way of affecting their influence. The vignettes provided a tool for capturing the stories being told as moments in time and space. They allowed me to study each

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<sup>555</sup> T. Tafoya, "Finding Harmony: Balancing Traditional Values with Western Science in Therapy," *Canadian Journal of Native Education* 21 (1995): 12.

<sup>556</sup> Harré, *The Singular Self: An Introduction to the Psychology of Personhood*, 3.

<sup>557</sup> F. M. Moghaddam and R. Harré, *Words of Conflict, Words of War: How the Language We Use in Political Processes Sparks Fighting* (Santa Barbara, CA: Praeger, 2010), 2–3.

<sup>558</sup> S. R. Sabat, "Prepositioning, Malignant Positioning, and the Disempowering Loss of Privileges Endured by People with Alzheimer's Disease," in *Words of Conflict, Words of War: How the Language We Use in Political Processes Sparks Fighting*, ed. F. M. Moghaddam and R. Harré (Santa Barbara, CA: Praeger, 2010), 101.

story individually and in relation to affect and meaning. Vignettes helped me to determine the categories they referenced or referred to. They supported decision-making as tangible representations for the participant to evaluate and appraise. They created nodes from which I could abstract theory.

Decision-making included exploring concepts regarding rights to access such as sharing and privacy. I had to find ways of describing what I meant and what the participant understood, not as a technicality but as a tangible process that we all do every day. It had to become a shared understanding. What might be shared, how, when and why? I used those understandings of private and public to assist with my decision-making.

A pertinent example of how decisions continued to be made, based on the changing meaning of the vignettes, was described in Chapter 5 Section 5.6. I described the concepts of secret and sacred in relation to how certain sensitive vignettes could be shared. Vignettes which had previously been inserted into a sealed section in the life book, were re-categorised by the participant. This decision was influenced by how the person felt about the story, and the story's impact on how Patrick felt about himself. In the final review of these sensitive stories, Patrick decided that it was no longer necessary to hide his stories – they could be kept with the other vignettes in his life book.

The concept of sacred is particularly relevant to the practice of ethical wayfinding. In this research, we were co-creating the contexts of embodied experiences in association with the explicit recording of personal stories. As a researcher and archivist, the person-centred approach was fundamental to developing meaningful relationships and working with participants in this research. Co-creating person-centred records reflected the application of theories and intent in the construction of records as tacit objects.

Scientific research has become a “complex process that now leads from pure scientific research to the production of artefacts, processes, [and] technology” which are always open to some future application outside its original context and scope. “If the context of a scientific research project is understood as what gives rise to or defines its aims, then in this sense, context will determine whether research is pure or applied...Science can be applied because artefacts while not naturally occurring are natural objects. As such they conform to our theories: indeed, they must, because they are designed in light of these theories” and not value neutral.<sup>559</sup>

A technology according to Forge is “knowledge of a technique – a way of doing something...the production of some artefact. An artefact, by definition, has a use or function; artefacts are produced for a purpose...artefacts actually have several purposes, which are in some kind of moral equilibrium...an artefact has (at least) one primary purpose, for which it was designed and made, and various secondary and derivative purposes.” Forge maintains artefacts are “value-laden as a consequence of their primary purpose. This does not mean that the value in question is necessarily ‘expressed’ when the technology is implemented and the

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<sup>559</sup> Forge, *The Responsible Scientist: A Philosophical Inquiry*, 33.

artefact made, but it does mean that the technology embodies the value – whatever this might amount to in actual practice.”<sup>560</sup>

Personal stories are potent in that they are both resilient and fragile. Their power, as demonstrated in this research, is in the processes for sharing the story as well as the co-created personal records. Working with vignettes as physical objects meant that I had to make transparent decisions about which events would become vignettes in the life book. The participants and I were able to review the stories as text and images together and explore the meaning. It was an exploratory exercise and a way of leaving, with each of the participants, those moments we had shared.

For ethical reasons there were some events which we studied as records in the interview process which would be treated differently or would not be documented within the life book. Though as described in Chapter 4 the life book had useful affordances when working with participants, it had its limitation in terms of ongoing use as a personal archive. I was able to study the concepts of access and sharing vignettes with participants but it was more difficult to create those controls in a paper bound records. Participants were progressively losing control of their environment and that meant possibly not having control over who could read what within the life book.

I concluded Chapter 5 by discussing how participants were conscious of how stories and records reflected on how they saw themselves and how they might be perceived by others. Participants were also conscious of the impact of the recorded story on people close to them. The stories and their management were considered in relationships to people. The findings in this research regarding the affective qualities of person-centred records have important implications. If records are to be truly person-centred, then the records should firstly address the needs of the person for whom they were created. Access to these records by others needs to have rigorous controls, not only in the broader contexts of care but also with members of family. It may not be possible for records to serve the needs of more than a single individual. I envisage cases where person-centred records are created only to support designing better care and services for an individual and not necessarily become part of a personal or family archive after the death of that individual.

Focusing on these particular records through spacetime (as described in Chapter 2), required contemporaneously considering the multiple roles and relationships, of potential users, to the person for whom the records were co-created.<sup>561</sup> Records continuum thinking considers records as having both enduring and perduring views: in that they have characteristics which are “both fixed and fluid”.<sup>562</sup> In response to these nuanced attributes of the records we were

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<sup>560</sup> Ibid., 48.

<sup>561</sup> Frank Upward argues for the concept of records as perduring objects. Rather than remaining the same across time and space, as is the case with notions of enduring objects, perduring objects “stretches out differently over spacetime”. See Hurley’s discussion with Upward described in C. Hurley, “Strength below and Grace above: The Structuration of Records,” 2011, 21,

<http://arrow.monash.edu.au/vital/access/services/Download/monash:155385/DOC>.

<sup>562</sup> Upward, McKemmish, and Reed, “Counterpoint Archivists and Changing Social and Information Spaces: A Continuum Approach to Recordkeeping and Archiving in Online Cultures,” 204.

creating I modified considerably the process for determining the levels of access and sharing amongst the participants. Each case was unique and required a personalised approach. This may be in some part due to the symptoms of dementia. It is also reflective of how any person has different ways of seeing and describing their world. How we understand access and sharing is contextual. It has the capacity to change depending on the way we are feeling, who we are with, and perceptions of self.

Co-creating person-centred records within certain contexts resulted in documenting things that were shared between the people who were present in the interview. Participants were making decisions about what they shared and with whom. Through reviewing the vignettes together the participants and I could discuss how these stories in the records could be shared with other people.

## 7.5 Conclusion

I described in this thesis how the process of co-creating person-centred records (as a particular type of record) and the social constructionist theory, which underpins this type of record production, was more than the production of records as objects. The storytelling process and co-creating person-centred records were also tacit and embodied experiences. As a researcher and archivist, I could not presume to know what meaning these activities had for the people who participated in the research. I implemented ethical wayfinding, along with a range of methods, and techniques in developing new knowledge of how people experience records and use them to support their own memory and identity.

The aims of this research were achieved in developing a social constructionist grounded theory of the Experiential Model of the Person-Centred Record. The research questions were guides to addressing key concepts in the situated context of the person with early stage dementia: perceptions and meaning of personal records in supporting memory and identity. In this chapter I have also discussed the ethical implications of these findings for theory and practice as a researcher and for archival science.

Co-creating person-centred records and supporting personhood was a theoretical and methodological position that I subscribed to. This position is founded on literature and discourses which reinforce my belief that an individual's experience is unique and contextual. My position is consistent with the social constructivist assumptions regarding the relationship between researcher and participants.

No human being can step outside of their humanity and view the world from no position at all...The task of the researcher therefore becomes to acknowledge and even work with their own intrinsic involvement in the research process and the part that this plays in the results that are produced. The researcher must view the research as necessarily a co-production between themselves and the people they are researching.<sup>563</sup>

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<sup>563</sup> Burr, *Social Constructionism*, 152.

The results of this study were influenced by the people who engaged in the research activities. The research outcomes reflect making decisions incrementally and reflexively in the context of human interactions. The participants and I were co-creating shared events and person-centred records through which personal experiences and meaning were interpreted and represented.

## 8 Conclusion: Developing Theory and Practice for Co-Creating Person-Centred Records

### 8.1 Introduction

In this concluding chapter, I build on the discussion in Chapter 7 in relation to the findings of this social constructionist grounded theory and reflexive research process. I will provide a summary of the major contributions of this research and discuss the broader implications for research, theory and practice. Limitations and opportunities are identified in relation to further research. This chapter is structured as follows:

- Section 8.2: Provides a statement of the contributions in each of the previous chapters of this thesis.
- Section 8.3: Provides a summary of the contributions to method achieved in this research.
- Section 8.4: A discussion of the key contributions of this research to archival theory and practice.
- Section 8.5: The limitations of this research are outlined.
- Section 8.6: Implications for future research are explicated across research theory and practice.
- Section 8.7: A vision for the future is presented.
- Section 8.8: Recommendations arising from the findings of this research.
- Section 8.9: Conclusion.

### 8.2 Thesis Overview and Addressing Research Aims and Questions

“It is hard to imagine the world without yourself.”

Psychotherapist Irvin Yalom spoke these simple yet profound words in a radio interview. He was speaking about how when contemplating our own mortality we cannot imagine the world without being in it.<sup>564</sup> As I listened to Yalom and reflected on my own research I was reminded that the participants in my research were incredibly aware of their ongoing presence being diminished due to illness and changing social contexts.

In addressing the research aims and questions, this thesis explored ways in which the person diagnosed with early stage dementia could be supported in maintaining an ongoing sense of

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<sup>564</sup> L. Malcolm, “The Talking Cure,” *ABC Radio National (Australian Broadcasting Corporation)*, accessed May 24, 2015, <http://www.abc.net.au/radionational/programs/allinthemind/>.

their presence and being, through shared memory-making and co-creating person-centred records. Participants were continuously positioning themselves in a shifting present while at the same time conscious of their relationship to past and future. This tension in many ways exemplifies the postmodern condition of multiple realities and changing social contexts. Perceived through the postmodern lens the world seems very uncertain. As a qualitative researcher, I was challenged to explore, theorise, and represent phenomena and perspectives as they occurred and continued to evolve.

In this postmodern landscape knowledge was both the foundation and the product of the research. What was known was itself questioned as the world strained existing frameworks; unique contexts where “knowledge is local and contextual”<sup>565</sup> were more complex than the whole. And, the quest for knowing led to the empirical realities of stories and narratives.<sup>566</sup> In this thesis I was able to explore the complexity of situated realities and the construction of meaning, through the perspectives of people with early stage dementia and their person-centred records.

The overarching aim of this research was to construct a second generation grounded theory of co-creating person-centred records in the context of early stage dementia. Further, to explore how second generation grounded theorising contributes to archival theory and possible implications for practice. In order to address this research aim, four exploratory questions were asked:

1. How do individuals perceive what is important in creating their own personal records in their current context of early stage dementia?
2. How do people represent their own memories and stories in ways that support the integrity of their identity and memory?
3. How is meaning supported and sustained in the process of co-creating records?
4. How do we achieve a rich understanding of the ethical issues and processes involved in this kind of record co-creation?

The research activities focused on understanding on what was important for participants; their perceptions and experiences at a time when they had an acute sense of their context. Co-creating person-centred records involved processes which supported sharing and representing personal stories. These processes facilitated studying the meaning of person-centred records and how these records supported memory and identity.

The second generation grounded theory approach and adaptive processes, at the core of shared memory-making and co-creating person-centred records within this applied research, were innovations in the way records are both studied and co-created. The findings provided new understandings regarding what it means to co-create records which are person-centred and support personhood. This knowledge contributed to existing archival theory regarding the nature and creation of records. The findings extended archival theory and practice into

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<sup>565</sup> S. Kvale, *Psychology and Postmodernism* (Thousand Oaks, CA: SAGE Publications, 1992), 202.

<sup>566</sup> Lyotard, *The Postmodern Condition: A Report on Knowledge*.



emergent, cross-disciplinary social contexts in which the integrity of identity and personhood is challenged.

This research is important because, though the concepts of personhood and person-centredness are promoted in the context of addressing the needs of people with dementia, the voices and perspectives of the person with dementia are underrepresented in research and in professional practice. Postmodern concepts of personhood underpinned the approaches to working with participants in this research and the co-creation of their person-centred records and consequently the study was focused on interpersonal processes and records as the product of these human relationships.

In addressing these concerns for how personhood and person-centred perspectives could be explored and understood, I drew on social constructionist literature within disciplines outside of archival theory to explore and create new archival knowledge of what it means to *co-create*. A social constructionist lens was adopted for exploring and understanding interpersonal and social processes in theory and the implications for practice. Applying a social constructionist lens in this study has created new theoretical and practice approaches for the study of records as social processes in archival research.

### **8.2.1 Overview of thesis chapters and contributions**

In Chapter 1 I positioned the research problem in the broader research context of the person with dementia and how the communal need to support personhood, memory and identity was conceptualised through diverse disciplinary lenses. In keeping with reflexive researcher practice I presented my personal and academic experience and how this has positioned me in the conduct of this research. This blend of research need and personal interest reveals a significant aspect about the process of developing theoretical sensitivity in second generation grounded theory. I regard this explication as an essential contribution in grounded theory work.

In Chapters 2 and 3 of this thesis I demonstrated how theoretical discourses across bodies of knowledge (postmodernism, personhood, social constructionism and records continuum theory) were both challenging and being challenged by the many notions of ‘reality’. Theories of personhood heightened concerns for a holistic understanding of being human versus the separation of mind and body which has, in many ways, influenced not only how we work with people but also how the material world, and records as part of that world, are understood. In Chapter 2 I was able to establish the relevance and fit of these diverse discourses into the third phase or archival era as described by Cook.<sup>567</sup> Additionally, in Chapter 2, I identified the key contemporary archival theorists and theories, upon which this research builds. In turn, the methodological approach and grounded theory generated in this research contribute to archival theory and practice.

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<sup>567</sup> Cook, “Evidence, Memory, Identity, and Community.”

In Chapter 3 I established the rationale for this second generation grounded theory as a methodology and in practice. I adopted postmodern theories and social constructionist lens, to interrogate assumptions of perception when working within this complex research environment where reflexive practice and ethical decision-making were processes for understanding meaning in situated contexts. This type of grounded theory approach connected to the development of processes for creating records has not previously been undertaken by other researchers and theorists.

Chapter 4 reports the chronology of processes, methods and techniques undertaken in working with participants and their data in this research. The processes were described in relation to the interviews which served to progressively explore participant perspectives. A key finding of this chapter was the complexity of the situated personal contexts for each person being interviewed. The nature of these contexts were powerful influences in the lived experience of each person and their perspectives of the world. These first findings influenced the way vignettes were co-created with each individual as person-centred records. I make the claim that there is an original contribution in the description of researcher and archival processes; which support person-centred practice in developing experiential and person-centred records (discussed later in this chapter).

Chapter 5 reported findings of grounded theory analysis in co-creating vignettes as unique perspectives and categories of meaning. The vignettes were reviewed with participants, to understanding their content, contexts and meanings. Further analysis and coding revealed how the co-creation and review of vignettes provided insight into generating shared understandings of these vignettes as representations of self. Key findings in Chapter 5 revealed that the world was at once internal and physical, social and material. These findings raised the consciousness of how plurality of meaning was represented through the co-creation of records as knowledge which was both tacit and explicit.

In Chapter 6 I reported the second generation grounded theory of the Experiential Model of the Person-Centred Record. The person-centred record is identified as a particular genre of record. The unique contribution is informed by the interpersonal processes and person-centred practice as identified in Chapter 4. Uniqueness is also generated through the development and use of the vignettes and categories of meaning within the record. Further, in the context of dementia, this type of record is defined by its capacity to support memory and identity.

Chapter 7 was an evaluative discussion of the theory and model generated in this study, with a particular focus on the qualities of a social constructionist research. This chapter integrates a reflexive discourse on ethical practice and the implications of this in qualitative research and the context of co-creating person-centred records.

### **8.3 Contributions to Method**

During the conduct of this research innovations in methods of data collection and data analysis were achieved. Predominantly, these innovations augmented methods commonly

used in grounded theory; they also complemented methods and techniques used in archival research. Four specific contributions are identified in the following sub-sections:

- Methodological wayfinding
- Ethical wayfinding: A person-centred approach in archival research and practice
- Co-creating situated contexts for person-centred records
- Mapping models and metaphors.

### **8.3.1 Methodological wayfinding:**

Methodological wayfinding was a term I used to describe the approach I took to designing this second generation grounded theory methodology in new and emergent contexts for research. Methodological wayfinding was a process of progressively and reflexively exploring the broader and situated contexts; in order to determine specific approaches to working with people and their records.

This wayfinding approach was a contribution to methods. The researcher is learning through the process; adapting themselves and the research methods used in conducting and interpreting findings. Ethical practice underpinned this adaptive process. It is important because the approach makes explicit the need to address the research problem while consciously navigating a range of dimensions which include: data, themes, theory, researcher, participants and stakeholders, as well as practitioners and experts in a range of disciplines, practice and theory.

### **8.3.2 Ethical wayfinding: A person-centred approach in archival research and practice**

The findings of this second generation grounded theory research have significant implications for archival research and practice; particularly in relation to ethical wayfinding which draws attention to reflexivity in decision-making, and person-centred practice. The term ‘ethical wayfinding’ was both coined and described in this research, as a reflexive and ongoing approach to researcher practice in working with people and their data. Ethical wayfinding as described in this research has particular relevance to the development of sensitive approaches in research methods and implications for practice.

In co-creating person-centred records with participants it was possible to explore realities, the meaning and significance of these records as social constructions. Social constructionists consider the creation of artefacts as activities of agency. By implementing a social constructionist lens in this research, I was able to engage in discourses which helped to understand the complex nature interpersonal processes involved in co-constructing person-centred records and their inherent meanings. These discourses challenge perceptions of ethics and decision-making as being discrete transactions. Decision-making was contextual and relational. Qualitative research which is emergent in its design and undertaking “make[s] it

difficult to anticipate what contingencies might arise at various stages of the research process, and to plan in any detail how ethical issues will be dealt with.”<sup>568</sup>

There are implications for researchers working within exploratory and flexible research designs. Ethical conduct at an operational level is generally defined as the strategies employed in protecting participants and their data.<sup>569</sup> Decision-making within emergent research contexts and working with people and their data becomes a more granular process. The challenge for researchers is to develop practices and tools for decision-making, where these decisions may be implicated, as contingency planning in an uncertain future. In a world that is changing so quickly the contexts may be difficult to imagine. Ethical decision-making becomes a shared and situated process.

### 8.3.3 Co-creating situated contexts for person-centred records

The grounded theory in this research explained how the relationship between people and personal recordkeeping is contextual and situated. For the people in this research, living with dementia meant that their contexts, roles and relationships were shifting and changing dramatically. Changing contexts impacted on the way these people saw themselves and the way they were perceived by others. Perceptions of self and others impacted on how decisions were made by, for, or with, participants.

Knowledge was a conversation. Truths and realities were constructed and situated in local contexts and as dialogues.<sup>570</sup> Studying the human relationship to personal recordkeeping required a holistic approach to working with people and records. Working with people over an extended period of time augmented the relationships between the archivist and the people with whom the records were being co-created. Getting to know people meant spending time with them, their family and their stories; it was also about people getting to know myself as a person as well as researcher.

This research was intentionally founded on notions of personhood as a philosophical and values based approach to working with people. Personhood was a term which itself encompassed numerous concepts to include the person, identity, self and personality. Theories of personhood focused on understanding personal perspectives and in the context of relationship between people. Though personhood as a concept was well founded in philosophy and commonly used in health care disciplines, it was new to archival science both as theory and in regard to its implications for practice.

In sharing stories of self and co-creating vignettes with participants it was possible to explore in detail the nature, meaning and significance of records as dynamic social constructions. The findings of this research suggested that there are records which can be more specifically described as person-centred. These characteristics were distinctive and reflected the person

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<sup>568</sup> M. Hammersley and A. Traianou, *Ethics in Qualitative Research: Controversies and Contexts* (London: SAGE Publications, 2012), Location 186, <http://books.google.com.au/books?id=L3SN8qUDfisC>.

<sup>569</sup> Hammersley and Traianou, *Ethics in Qualitative Research: Controversies and Contexts*.

<sup>570</sup> Rorty, *Philosophy and the Mirror of Nature*.

represented within. Person-centred records embodied characteristics of personhood; that is, autobiographical stories and sense of self, personal points of view and perspective on the world. Personhood and person-centred records were the activities and product of co-creation as both social and intersubjective processes. The person-centred record was both the representation and the interpersonal process of co-creating the record.

The person-centred record was created in relationship with participants and through the construction of supportive practices for decision-making. The usefulness and purpose of these records was defined in relationship with the persons with whom the meaning was being created. This correlates theories of personhood with records continuum theory. Records continuum theory emphasises the need to understand the purpose and intent for which records are created as well as used. The purpose of the person-centred record was to represent the personal perspective, the voices of the person for whom the records were being created. It was a process for privileging the person whose voices and stories may be absent from existing records and environment.

This notion of the person-centred record has implications for both theory and practice. The type of record created was influenced by the philosophical intent of the research process and reflexive practice. Of equal importance, the type of record produced reciprocally affected the participants and the context of its creation. The researcher/archivist was co-creator of relationship, personal knowledge and the person-centred record. The archivist was not neutral. In this study context the archivist was positioned and aligned with the participant in the research. The person-centred record was created in relationship to the person. It was sacred.

The affective nature of records raises important concerns regarding archival processes for co-creating records and the way these records are annotated and used. The way participants' experienced co-creating person-centred records was shifting and changing. These findings reflected the mutable nature of individual perspectives, decision-making and records.

### **8.3.4 Mapping, models and metaphors**

Conceptual mapping was used to create, analyse and represent data. Mapping facilitated exploring relationships amongst diverse levels and categories of concepts.

- Core literature was analysed and mapped to explore the archival concepts and associated discourses.
- Extensive stakeholder engagement was mapped to analyse not only the activity I had undertaken but to develop learning from the processes and the outcomes.
- Aspects of the research process and the participant data was recorded and organised using mapping in preparation for further analysis and reporting.

Modelling was used to define high level concepts in their relationships to each other.

- Models were developed to illustrate the processes I undertook in the research.
- Models also provided a powerful way to synthesise the analysis of that process and findings of the data analysis.

Metaphors were used to communicate the characteristics that two seemingly different concepts may actually have in common.

- Metaphors were used in this thesis as a way of illustrating sometimes complex or abstract concepts in alternative ways.
- Some of the images I used in developing models and drawings were metaphoric in that visually they communicate another layer of symbolism and meaning to the linguistic content.

Based on the experience of this research, I believe that the use of mapping, models and metaphors as methods are a significant contribution to archival research and second generation grounded theory.

## **8.4     *Key Contributions to Archival Theory and Practice***

This second generation grounded theory is an exemplar of applied archival research which has achieved major new contributions to knowledge. The principle contribution is that this is the first social constructionist grounded theory of the Experiential Model of the Person-Centred Record. Within this theory and model, the concept of the person-centred record as a particular genre is original. Within this process, theory and practice brought together a unique repertoire of methods and techniques for both working with people and for co-creating records to develop theory using the social constructionist lens.

### **8.4.1    *Achieving a social constructionist grounded theory of the Experiential Model of the Person-Centred Record***

This research produced the first grounded theory of the Experiential Model of the Person-Centred Record. A key outcome of this grounded theory model was proposing the person-centred record as a new genre of record within archival theory and practice. The grounded theory of the Experiential Model of the Person-Centred Record was contained within the specific context of early stage dementia and contained heavily saturated categories. The dimensions in the model, though derived from data obtained during the research, also have resonance within the cross-disciplinary literature. Significantly, while the dimensions have resonance in the literature, the way these dimensions are brought together in the model is unique. The model as it was conceptualised extends knowledge of our relationships in the world both socially and materially. The need to study human relationships to the material environment is supported in social constructionist literature which in the most part has focused on interpersonal processes.

The Experiential Model of the Person-Centred Record contributed to knowledge of what it means to co-create records. The Experiential Model of the Person-Centred Record conceptualised key findings regarding the human experience of records as a social object. The situated contexts of the person with dementia, the roles of records and their relationship to personal recordkeeping were all changing. These changes were not due solely to dementia but the shifting roles and relationships with other people and their immediate environment. It

became evident that within these overarching concepts, there were contexts, practices and processes which were in themselves able to alter the nature of and relationship to records. Sharing knowledge was a process for making explicit the personal constructs through which we understand ourselves as social beings. Records had the capacity to affect but also be affected. Person-centred records were an extension of self and a way of evidencing perspectives where they might not otherwise be voiced or heard.

The Experiential Model of the Person-Centred Record was generated as a conceptual model. The model integrates the human and recorded dimensions of co-creating records as a story sharing activity. As a framework, the Experiential Model of the Person-Centred Record facilitated perceiving the person-centred record as an extension of self; a record which is at the same time an expression of identity and reflects the embodied experience of identity and meaning. It is a way of knowing self and communicating knowledge of self.

The Experiential Model of the Person-Centred Record is a provisional model in that it was defined within particular participant contexts and supported by underpinning postmodern theories. In practice the Experiential Model of the Person-Centred Record is a way of pointing to meaning in autobiographical stories and records of self; they are both defined and explored through story content and meaning. The model could be critiqued for not explicitly including certain dimensions such as gender, race and culture. The purpose of the model was not to categorise the person but rather reflect their own sense of identity and meanings.

As a tool, I believe that future versions of the model could be adapted to encompass further contexts and purposes. It is important to note that the Experiential Model of the Person-Centred Record, can also guide and challenge researchers and archivists in making explicit their own assumptions and offer unique perspectives in relation to others.

The above achievements were generated by the development of the Experiential Model of the Person-Centred Record and support four developments in archival theory and practice. These are:

- The usefulness of a social constructionist lens to assist the explication of what is personal within the record.
- Innovation in archival research and practice.
- Co-creation of a theory for practice.
- Theoretical advancement.

#### **8.4.1.1 A social constructionist lens assists explication of the personal**

In Chapter 2 I presented an analysis of contemporary archival theories that had relevance to the concept of the personal record. When these were considered in light of the challenges of memory, identity and the experiences of people with dementia, the quest of generating person-centred records was apparent. The very specific setting and intent of this research, is essential to the theoretical project. An integral part of the research is in understanding, explicating and theorising the nature of the *personal* in records and their intrinsic relationship to person, to memory and to identity.

I employed a social constructionist lens, founded in psychology and social psychology, to the study of interpersonal relationships and importantly their impact on practice in co-creating records. Adopting bodies of theory from across disciplines brought new theoretical lenses from which to influence and develop archival research and practice. This created a unique conceptual framework within which the research was underpinned and positioned.

#### **8.4.1.2 Innovation in archival research and practice**

Designing a second generation grounded theory, with a toolkit of methods and techniques, allowed me to respond to emergent contexts and concerns as they arose. The implications for research practice were evident in the participatory epistemology I used with participants. I implemented techniques for making explicit interpretations and meaning of participant data through personal mapping, the creation and review of vignettes.

Innovation in practice resulted in a novel implementation of methods and techniques in this grounded theory research.

- Research
  - Second generation grounded theory as a methodology is most commonly used for the study of interviews, text and observation. The methods and techniques for co-creating and reviewing vignettes with participants provided nuanced insight into those stories and specific meanings for the people interviewed.
- Archival practice
  - The study of co-creating records as interpersonal processes and tangible objects drew on methods and techniques which illuminated the ways in which people were both able to affect and be affected by records.
  - The need for archivists to be actively engaged in the creation as well as management of records has been reported in archival literature. This project is the first applied study of the process of co-creating person-centred records.
- Working with participants with dementia and their families
  - The importance of developing researcher empathy as a sensibility and skill which influences practice.
  - Research processes and practice for:
    - Co-creating and reviewing records which demonstrate the subjective nature of memory and personhood as socially constructed.
    - Interpreting and translating the human experience into data for analysis.
- Decision-making was a reflexive activity influenced by developing explicit theoretical knowledge as well as tacit experiences
  - Understanding the paradigms associated with the research context were fundamental to explicating how decisions were made.
  - Decision-making was the act of considering the needs of individuals involved in the research.
  - Decision-making was supported by methods and techniques for making explicit the decision-making processes for both participants and the researcher.



Together, all these methods and techniques resulted in innovation during the conduct of archival research and practice. This thesis (particularly Chapters 3 to 6) explicates these aspects in some depth. This creates the possibilities for other archivists and grounded theory researchers to follow and further assess the processes for ongoing archival work.

#### **8.4.1.3 Co-creation as a social practice theory**

This applied research and grounded theory of the Experiential Model of the Person-Centred Record is a theory for practice. It extends archival knowledge, in particular, with regard to the human relationship to records. The application of a social constructionist lens was a new approach to developing archival theory. Social constructionism as a postmodern paradigm, was particularly suited to the study of the situated contexts and perspectives of people. Social constructionism provided an ontology and language for analysing the processes of co-creating person-centred records as acts between people.

This grounded theory extends and contributes to records continuum theory and models by highlighting the interpersonal and social relationship of people and records as a co-creation. Working with people, in a way that attended to their personhood, in the context of this study informed how the research was conducted and the person-centred records were co-created.

#### **8.4.1.4 Theoretical advancement**

In Chapter 2 I identified the emergence of contemporary conceptualisations of records around the postmodern turn. These include records continuum thinking, working with complexity, structuration theory, pluralisation and records as memory. The findings of this thesis fit within these paradigmatic perspectives. This social constructionist grounded theory of the Experiential Model of the Person-Centred Record makes a specific and original contribution to this theoretical genre of work.

The theoretical contribution of this work includes:

- The widened lens of second generation grounded theory and social constructionism; these assist in deeper exploration of what is personal, processes of co-constructing, human experiences of temporality.
- The grounded theory itself assists contemplation and integration of the physical, emotional, philosophical and spiritual aspects of the person-centred record; this assists in interpreting and representing these dynamics with the human experience.
- Methodological and ethical wayfinding processes; while central to this grounded theory research, these hold equivalent resonance and power within the archival processes of generating person-centred records.

In addition, I expect that the work contained in this thesis and the outcomes of this research will generate further dialogue with researchers and archival theorists working in emergent and contemporary contexts. The findings of this applied research emerged through the situated context of co-creating person-centred records with people with early stage dementia. These

understandings of person-centred approaches to working with people and co-creating records have relevance to other situated contexts, where the qualities of records are challenged with regard to how they reflect and represent the personal experiences of people to whom they refer.

## **8.5     *Limitations***

The findings and contributions of this research were limited by procedural and contextual aspects of the study. Firstly this was a second generation grounded theory study conducted in the context of working with each of three participants over a contained time frame (over three months).

The research findings were shaped by the perspectives, experiences and lives of these three participants. The limitation is that other participants may bring different perspectives, other experiences and unique lives. It is unknown whether any similarities or differences would change the results of this research.

The research was contained by the assumptions of second generation and constructivist grounded theory. The research was theoretically framed by four cross-disciplinary concepts of postmodernism, records continuum theory, personhood and social constructionism. The derived grounded theory of the Experiential Model of the Person-Centred Record was developed through levels of coding (thematic coding, open and selective coding, and conceptual mapping). Due to the validity constraints of grounded theory, findings from this study may be transferable but they are not generalisable.

## **8.6     *Implications for Future Research: Developing Theory and Practice***

The implications of this grounded theory research cover the key areas of research, theory, practice and technology. Future research would extend the contexts and methods used in this study. The theory requires critique and development in relation to the extended contexts and disciplines. The theory of the Experiential Model of the Person-Centred Record needs to be translated into discourse and practice for archival and health care professionals.

### **8.6.1   *Implications for research***

Three key implications for further research arise from this study. It is important that this research is replicated in other contexts, with other participants and in different timeframes. This is important as it will indicate what findings from the research transcend people, time and place and which findings vary in these changing contexts. The more replication research is undertaken, the more likely we are to identify the sustainable theoretical and practical aspects of creating and using person-centred records.

In addition, the research approach needs to be explored in similar and different human and interpersonal contexts. For example, would working with people with other disabilities require different ways of undertaking person-centred activities or different media for the generation of person-centred records? It would be interesting to know if adopting different models of research, different methodologies and alternative conceptual framing would generate different answers to this research problem.

There needs to be further exploration of the methods of methodological wayfinding and ethical wayfinding in archival practice and research. Based on these explorations these methods may be further clarified and extended. Further dialogue about the practice implications within research is required. A meeting with a community of scholars may assist this development.

### **8.6.2 Implications for theory**

There are multiple implications for theory arising from this research. Some have been explicated in the previous sections of this chapter. Below is a list of items which are suitable for a theory development agenda:

1. The Experiential Model of the Person-Centred Record has the possibility of informing a new genre of record in theory and practice.
2. The components of the grounded theory require further critique and development.
3. The model itself requires theoretical modelling and testing.
4. The theory needs to be tested in archival contexts by archivists.
5. The grounded theory requires further work in relation to records continuum theory. Specifically, further research is required to explore the implications of these findings in relation to existing records continuum theory, and then translating the findings into archival practice and technologies which are person-centred.
6. Further theoretical work is required around the practice and theory of ethical wayfinding within the context of co-creating person-centred records.
7. The genre of the person-centred record requires further explication and development.

### **8.6.3 Implications for practice**

Implications for practice arise from this research. The context of co-creating records creates challenges with regard to ethical practice, how researchers work with people as well as their records. This type of applied research inspires new opportunities to design methodologies which help understand the complexity of the human relationship with records.

The early findings in this research highlighted the significance of affect, feeling and emotions, encounters and relationships in supporting personhood. These findings provided a key to exploring the production of person-centred records as powerful social objects embodied with dimensions extending beyond the representation of content and descriptors. The study and creation or use of person-centred records cannot be separated from the person. It requires a multidisciplinary approach to the development of knowledge, practice and protocol. The creation, use and management of records for supporting personhood research needs be studied in collaboration with diverse disciplinary experts. It requires the tacit and explicit

knowledge of archivists, philosophers, psychologists, social psychologists and information management professionals.

In light of the findings of this study archival professionals need to consider practices in relation to co-creation of records and consultative approaches to decision-making. It is important that this research should stimulate dialogue between archival professionals to explore differences between prevailing and predominant practices and the practices associated with this grounded theory model.

It will be important to have training and education programs for practitioners working with person-centred records in relation to the Experiential Model of the Person-Centred Record and other methods identified within this research. Further, if this research is to have application in the context of dementia then archival professionals needs to discuss and strategise ways of working with participants who have impaired cognition.

#### **8.6.4 Implications for technology**

I understood the complex practice settings where personal stories and person-centred records could be leveraged through systems, archival and technological, for supporting the person with dementia. What became evident in the context of this research project was that we need to understand the way people can both affect and be affected by records of self before designing systems which further institutionalise the records.

Future development of theory and practice would require bringing together an interdisciplinary team to reflect the human, archival and technological dimensions of the research. It is also important to translate these findings into practice and guidelines for archivists and other practitioners who work with people and their records to support personhood, memory and identity. These may require technological developments in the future.

### **8.7 Recommendations**

The following recommendations arise from this study. It is recommended that:

Recommendation 1: This study should be replicated in design and context.

Recommendation 2: The grounded theory for the Experiential Model of the Person-Centred Record should be tested in theory and in application.

Recommendation 3: The practices for decision-making and co-creating person-centred records as identified in this study should be adapted and applied in future archival work.

Recommendation 4: A meeting with a community of scholars should be convened to assist the development of guidelines based on the findings of this research for future archival practice and theory.

Recommendation 5: The principles of ethical wayfinding should be further explored in relation to research on the person-centred records and archival work.

Recommendation 6: The grounded theory model of the Experiential Model of the Person-Centred Record needs exploration in relation to records continuum theory.

## 8.8 *Vision for the Future*

On completion of this research, I imagined a new future where person-centred records could function in the lives of people with dementia and their carers. In this section as I near the end of the thesis I share some images and reflections on what this future might look like.

During this research I acquired a new phone with an interface that displayed icons and a search bar. These simple navigational concepts changed my thinking in relation to how we could use technology to both organise and use information. I drew inspiration from the phone's simple interface design, based on the ability to search or browse information, to conceptualise just how this technology might be used in relating to or caring for people. I was also conscious of practice settings where staff are time poor and with varied abilities in literacy or the use of technology.

I envisaged a device which could be used by a person to recall their own personal stories or memories when this capacity is diminished to the point of communicating only fragments of their world. Imagine:

- Being able to respond to a person's call for a name by searching and finding that name in an archive of personal knowledge.
- Wanting to talk to the person about their immediate family members and selecting the icon that says 'Family' to reveal the faces, names and relationship to the person.
- Looking for the icon which says 'Music' and being presented with the person's favourite recordings ready to play.
- Being able to annotate records with the person's response to the content of the records.
- Being able to capture affect as observed or experienced.
- Being able to add new events and states of being.
- Accessing records discretely according to roles and permissions.
- Using the records in this type of personal archive to plan and care for the person.
- Creating a place to document stories of who the person is and their perspectives but needing to engage with clients to access information quickly and efficiently.

Co-creating person-centred records in this research, was a continuum of storytelling and producing records with physical properties. I deliberately contemplated the characteristics

listed above in relation to what would be their logical properties in a digital environment. This type of ‘what if’ thinking was a useful technique for constructing theories and building models.<sup>571</sup> It took what happened in a situated practice and abstracted out so that the implications of the learning could be applied beyond its immediate context. It was reflexive and part of an ongoing cycle of critique which was tolerant of limitations in the research process but the theorising was not constrained by these limitations.

This second generation grounded theory research explored the nature of the person-centred record with three people diagnosed with early stage dementia. In-depth interviews and innovative processes for co-creation were implemented to studying the way personal records are both studied and created.

This knowledge opened up opportunities to contribute to existing archival theory and practice. The findings extended the practice of the records and archival professionals into emergent social contexts in which the integrity of identity and personhood is challenged.

## 8.9 Conclusion

In conclusion, this research has generated a grounded theory of the Experiential Model of the Person-Centred Record. The theory was generated within the context of early stage dementia through co-creating records with three participants. The perspectives, lives and experiences of the people with early dementia shaped, informed and led to co-created person-centred records. The second generation grounded theory as a methodology supported analysis and coding of archival practice which lead to development of the social practice theory. The theory has direct implications for ongoing research and development of archival practice related to co-creation of personal records. This second generation grounded theory potentially creates the basis for a new genre of the person-centred record within archival theory and practice. In conclusion I acknowledge and thank the participants in this research whose circumstances informed the research. This study makes an original and significant contribution to archival science and the study of person-centred records.

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<sup>571</sup> Jaccard and Jacoby, *Theory Construction and Model-Building Skills: A Practical Guide for Social Scientists*.

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## Appendix 1 Human Ethics Approval



**MONASH** University

Monash University Human Research Ethics Committee (MUHREC)  
Research Office

### Human Ethics Certificate of Approval

**Date:** 8 April 2011  
**Project Number:** CF10/3507 - 20110001867  
**Project Title:** The storyline project: Determining a therapeutic use for the personal archive  
**Chief Investigator:** Prof Susan McKemmish  
**Approved:** From: 8 April 2011 To: 8 April 2016

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#### Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.



Professor Ben Canny  
Chair, MUHREC

cc: Assoc Prof Cheryle Moss, Ms Joanne Mihelcic

Postal – Monash University, Vic 3800, Australia  
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton

[www.monash.edu/research/ethics/human/index/html](http://www.monash.edu/research/ethics/human/index.html)  
ABN 12 377 614 012 CRICOS Provider #00009C

## Appendix 2 Informed Consent Form (Participant)



### Group 1 Participant - Informed Consent

Title **The Storyline Project: Determining a therapeutic use for the personal archive**

Yes <input type="checkbox"/>	No <input type="checkbox"/>	I consent to be a subject of a recorded interview to be undertaken by Joanne Mihelcic and I understand that the purpose of the research is to investigate her PhD thesis topic: <b><i>The Storyline Project: Determining a therapeutic use for the personal archive.</i></b>
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I agree to take part in the above Monash University research project. I have read the Explanatory Statement, which I will keep for my records. I understand that agreeing to take part means that I am willing to be interviewed over a series of several weeks.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I understand that for the purpose of this project my personal data must keep all identifying information for it to be useful to me and to the researcher when analysing the data.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I understand that my personal data will be deidentified for the purpose of reporting.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I understand that my participation is voluntary and that I can choose not to participate in the project at any stage without being penalised or disadvantaged in any way.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I understand that a carer or family member must be present in my home during the course of the interviews.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	Should I withdraw from the project during the interview process; the use of information collected from the interviews will be decided in consultation with me.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I agree to the interview being audio recorded.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I agree to the interview being video recorded.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I understand that given the topic of the research, I could possibly experience some emotional distress. I also understand that arrangements have been put in place to offer me the necessary support should this occur.
Yes <input type="checkbox"/>	No <input type="checkbox"/>	I take part in the research with the understanding that the information I provide will be used specifically for the purposes of this project. However, I also understand that the data collected may be used in other research for the purpose of investigating the use of a personal archive. Should this be the case, the researcher will contact either myself or my advocate (as I have nominated below) to seek approval prior to any information being used.

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P1/2\_STLN-C0001

I **DO / DO NOT** consent to being contacted for potential future follow-up interviews for either this thesis or a future work resulting from this research project.

Name: .....

Address: .....

Email/Phone: .....

Signature: ..... Date: \_\_\_\_/\_\_\_\_/20\_\_

**Nominated Advocate /Power of Attourney**

I nominate the following person to be able to act on my behalf with regard to the management of my personal archive if I am unable to make that decision.

Name: .....

Address: .....

Email/Phone: .....

Signature: ..... Date: \_\_\_\_/\_\_\_\_/20\_\_

**Independent Witness**

I certify that the project has been described as per the explanatory statement to <insert Group 1 participant's name>.

Name: .....

Address: .....

Email/Phone: .....

Signature: ..... Date: \_\_\_\_/\_\_\_\_/20\_\_

P2/2\_STLN-C0001

## Appendix 3 Sample Questions for Interview

### Participant Interview Themes/areas to be covered

**These are examples of openers and I expect that the results will influence subsequent interviews rather than prescription for a semi-structured interview.**

#### Your Personal History

Could you tell me some details about yourself?

- Could you tell me how old you are?
- When were you diagnosed with Alzheimer's Disease?
- What are the things that concern you most at this point?
- Could you tell me about yourself?
  - Your family
  - Special events in your life
  - Your work
  - Special Achievements
  - Your hobbies
- How long have you been living in this home?
- Can you describe what makes a home special to you? This could be a previous home or where you live now.
- Could you tell me about your favourite place at home or elsewhere?
- What are the things you like to keep around you because they are meaningful and have a special significance?
- Are there memories or stories that are precious to you?
- Can you tell me about these?
- Are there possessions that remind you of these memories?
- Why are these memories and possessions important to you? What do they represent for you?
- Are there possessions that you regret having lost over time? Can you tell me why?

#### In review of the interview data:

- Are you satisfied with the way your story has been represented?
- Would you like to change anything?
- Are there people you would like to share this story with?
- If so, who would you share it with?
- Would you be happy to share this now or only at a specific time?
- What would you like to have happen to your copy of the archive?
- What would you like to have done with the data collected in your interviews?

## Appendix 4 Recruitment Channels

Organisation	Media	Response
Alzheimer's Australia, Victoria	Call for participants posted on website and in the newsletter	2 people – both in rural Victoria
National Dementia Research Forum	Call for participants information sheet	2 people via Commonwealth Respite & Carelink Centre – Southern Region
<i>Monash University News</i>	News article with contact details for further information regarding the project or participation.	1 person
Health Canal	News article with contact details for further information regarding the project or participation.	0
<i>Aged Care News</i>	News article with contact details for further information regarding the project or participation.	0
Radio National Far North Queensland	Radio interview	0



# Appendix 5 Poster: Review of Extensive Stakeholder Engagement

## Review of Extensive Interdisciplinary Stakeholder Engagement

during the first year of the

Storyline Project: Determining a therapeutic use for the personal archive in aged care & dementia

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### The Context

Emergent technologies and a student researcher with interdisciplinary background create an opportunity to influence both the design and outcome of new research in the convergent space of information technology, Alzheimer's disease and aged care.

Working as a solo researcher in this multidisciplinary framework reinforces the need to draw on a range of expertise to understand what the issues are and how they can be investigated. This is particularly important when determining research objectives that cannot be addressed by one single discipline.

### The Project

The aim of the Storyline Project is to create, share and manage a personal archive for the person with Alzheimer's disease to support their memories and identity. The personal archive is a register of images and stories that are important to the individual.

#### The research objectives are to:

- Understand what the individual perceives is important in terms of creating their personal archive and how they would like to share this content in different contexts.
- Develop a model by which people in the early stages of Alzheimer's disease can create and be supported in creating a personal archive.
- Define the information management and archival questions in relation to the creation and management of this type of personal record.

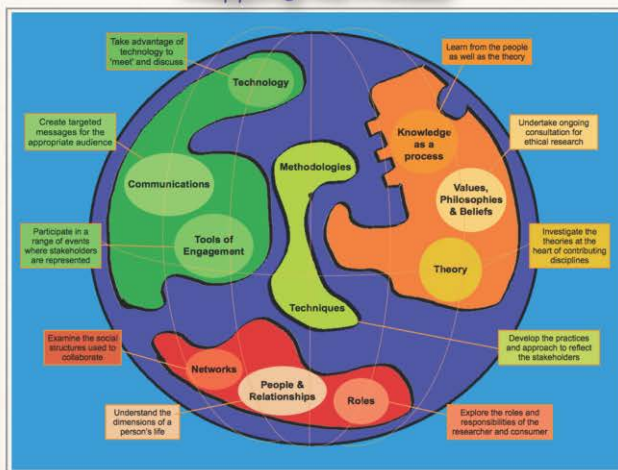
### The Activity of Stakeholder Engagement

Provides an iterative approach to concept building and research design in relation to real world theory and practice.

It creates opportunity to:

- ★ Define the research problems in relation to the relevant disciplines.
- ★ Challenge and refine the research problems, methodologies and protocols in a way that is value sensitive.
- ★ Validate these research concepts with experts so that the concepts make sense in the real world both theoretical & practical.
- ★ Scope the project into something that can be done within the framework of a PhD project and thesis, undertaken by a single person.
- ★ Design and build a project that meets a range of criteria and needs: methodological, philosophical & pragmatic when working with people with Alzheimer's disease.

## Mapping the Process



### Stakeholders as a Unit of Analysis

One single perspective does not represent all of the possible stakeholders in a research project.

Emerging research environments that involve multiple disciplines create the challenge of identifying stakeholders at an individual, community and organisational level who represent the personal, academic and practitioner perspectives.

### The Experience of Networking as a Way of Learning & Discovery

- Define the research problem as an environment of people, physical spaces, interactions and activity.
- Determine the disciplines, special interest groups and associations that are working this environment.
- Synthesise the project concept in a single brochure.
- Participate in relevant conferences.
- Introduce yourself to people: individuals & representatives of associations, disciplines and consumers.
- Learn to pitch the research concept so that it can be discussed quickly.
- Take note of feedback and ideas.
- Iterate the project design with the feedback.
- Follow up by meeting with individuals as expert advisors.
- Support the cause by participating in relevant associations.
- Take advantage of the technology for staying in touch and communication.
- Apply for scholarships outside your principle discipline of study.

### A Consultative Approach to Research Design

This is a qualitative study with interpretivist approach. The techniques and design of the Storyline Project have been strongly influenced by the sensitivity of both the research topic and the needs of the research participants.<sup>1</sup>

Ethics in this project is an approach that considers the philosophical and practical needs of the participant who is made vulnerable by a disease which leads to confusion and memory loss.

Feminist and post-modern frameworks have influenced the approach to research design by focusing attention on those participating and how their choices may be valued and protected.

These same feminist characteristics are espoused by second-generation grounded theorists who were the early students of Glaser and Strauss. They have in practice allowed the methodology to evolve and change according to the research and the disciplines involved.<sup>2</sup>

Grounded theory promotes a methodological process for data collection and analysis that allows the refining of data collection through shaping and reshaping. It is a way of thinking about data and what arises from the data.

Activity theory creates a frame for understanding the complexity of human activity as socially situated and the unit of analysis.<sup>3</sup>

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# Appendix 6 Mapping Literature

