

Question guide for qualitative focus group interviews with metastatic breast cancer patients

A. Opening questions

1. Please begin by presenting yourselves by your first name and briefly tell the group:
 - a. When you were first diagnosed with breast cancer?
 - b. When you were diagnosed with metastasis (and at which hospital)?
 - c. The current state of affairs with regard to the metastasis?

B. Quality of life issues

2. Please try to describe how the breast cancer is affecting your quality of life (probe for examples and domains):
3. Physical well-being, symptoms and treatment-related side effects
 - a. → impact on QoL and functioning?
4. Have you felt that your cognition – e.g. memory or concentration – has been affected?
 - a. → impact on QoL and functioning?
5. Has getting breast cancer affected your relations with others – how?
 - a. Your family life
 - b. Your love life
 - c. Your relations to friends and acquaintances
6. Has getting breast cancer changed your body- or self-perception/identity – how?
7. How would you describe your emotional/psychological well-being today?
 - a. How did you react to learning that the breast cancer had spread?
 - b. What are your main current (disease-related) concerns
 - c. → impact on QoL and functioning?
8. How would you describe your overall daily functioning today?
9. What matters most to your daily quality of life (physical, social or emotional factors)?
10. Has your quality of life changed from when you were diagnosed until today – how?
 - a. Have your priorities changed over the course of disease?

C. Treatment experiences and needs

11. Which types of medical treatment have you received since getting metastatic breast cancer?
 - a. Do you know why you have received these types of treatment?
 - b. Have you been involved in the choice of treatment – do you want to be involved?
12. Would you say that treatment in itself has affected your quality of life (positively/negatively)?
13. Do you feel you have to weigh prolongation of life against your daily quality of life – how?
 - a. Which factors affect your priorities?
14. Have your treatment and care priorities changed over time?
 - a. Have your threshold of tolerance with respect to side effects changed along with the progression of disease – why?
15. Do you feel that your (medical) treatment needs are being met (incl. symptom management)?
16. What do you feel are your greatest needs with regard to treatment today – and why?

D. Additional needs for support and care

- E. What are your most important non-medical needs for care and support today – and why?
- F. Are there any kinds of non-medical care needs that you have lacked since developing metastatic disease?
- G. Have you discussed your quality of life and non-medical issues with your physician?

H. Closing questions

- I. Are there important issues that you feel we have failed to discuss for us to leave with a comprehensive understanding of your care and treatment needs?

Table 1. Participant characteristics

FG1 Partici- pants*	Current age (years)	First breast cancer diagnosis	Metastatic breast cancer diagnosis and metastatic site	Treatments (patient reported)	Partner status	Children and grand- children	Occupation
FG1A	69	1995	2007 Pulmonary pleurae Liver Bone (sternum, costae)	CH	Single	2 AC 6 GC	Pensioner
FG1B	60	2007	2009 Bone (vertebra, and later: hip, pelvis, other vertebras) Brain	CR Trastuzumab	Married	3 AC 4 GC	Disability pensioner since 2010
FG1C	56	2010	2014 Bone (3-4 vertebra)	CHR	Married	3 AC 3 GC	Unresolved: sick leave/ wants flex job Volunteer work
FG2							
FG2A	50	2003	2014 Bone (all) Pulmonary plurae Lymph nodes (thoracic)	CHS	Married	1 UC	6h flex job
FG2B	49	2001 (BRCA2)	2013 Liver Pulmonary plurae Lymph nodes Chest bone	CHRS	Married	3 AC 3 GC	Disability pensioner since 2002
FG2C	71	1995	2008 Sternum Pulmonary plurae 2014: Bone (vertebral column) 2016: Liver	CHRS	Single	1 AC 3 GC	Retired since MBC diagnosis
FG2D	46	2003	2005 Bone (gradually all: vertebral column, thighbone, pelvis)	CHRS Trastuzumab	Married	2 UC	Disability pensioner with 6-8h flex job
FG3							

FG3A	54 år	2010	2012 Ovaries 2014: lungs and lymph nodes (thoracic, armpit)	CHRS	Re-married	2 AC 1 step GC	Unresolved, process of disability pension Volunteer work
FG3B	66	1998	2014 Bone (lower back, chest bone) Adrenal glands 2016: Liver	CHRS	Married	2 AC 4 GC	Undisclosed
FG3C	69 år	2000	2012 Pulmonary plurae lymph nodes (thoracic) 2015: Liver, vertebrae	CHS	Single	2 AC 4 GC	Early retirement before MBC diagnosis
FG4							
FG4A	50	2007	2009 Liver Hip 2015: lymph nodes 2015: kidney	CHRS (+Radio frequent ablation)	Re-married	1 UC 2 step AC 2 step GC	Disability pensioner with 16½h flex job Volunteer work
FG4B	54	2013	2013 Bone: Vertebral column, hip	CHS	Married	1 AC Step GC	10h flex job
FG4C	41	2006	2013 Liver Pulmonary plurae Bone: Pelvis , hip, vertebrae Lymph nodes	CHRS	Married	2 UC	Disability pensioner Volunteer work
FG4D	48	2004	2007 Pulmonary plurae Lymph nodes (thoracic)	CH Trastuzumab	Single	2 AC	16h flex job
FG5							
FG5A	72	2008	2014 Lungs Bone (vertebrae)	HRS	Non-cohabiting partner	2 AC 4 GC	Pensioner
FG5B	42	2015	2015 Breast	CH	Married	1 UC	Full time work

			Lungs Liver Bone (pelvis)				(flexible hours)
FG5C	62	2007	2012 Lymph nodes by the collar bone Bone (sternum, vertebra) Pulmonary plurae Both lungs 2014: brain	CHRS	Re-married	2 AC 2 step AC 3 GC + step GC	Early retirement since 2008
FG5D	71	2009	2014 Bone (chest, thighbone) Lungs	CRS Trastuzumab	Married	4 AC	Pensioner

*Participants resided in 17 different cities/towns from Frederikshavn to Sønderborg (N/S) and Esbjerg to Copenhagen (W/E).

Abbreviations:

FG: Focus group. Regions: Northern Jutland, Southern Jutland, Central Jutland, Zealand, and Funen

Treatments: C: Chemotherapy; H: Hormone therapy; R: Radiation therapy; S: Surgery

Children and grandchildren: UC: underage children; AC: adult children; GC: grand-children

Figure 1. Main topics and subthemes to patients with metastatic breast cancer

