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The Use of Preference Techniques to Value the Health Gains from Treatment: Kaposi's Sarcoma

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**The Use of Preference Techniques to
Value the Health Gains from Treatment:
Kaposi's Sarcoma**

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Abstract

Aims: To investigate preference techniques to value potential health gains from treatments of Kaposi's sarcoma (KS).

Patients and Methods Face-to-face interview of a sample of men with a history of HIV/AIDS (N=15) or HIV/AIDS and KS (N=17). The main outcome measure was Quality of life (QoL) associated with various KS disease states expressed on a scale from 0 (death) to 1 (perfect health) obtained through time trade off (TTO) and rating scale techniques.

Results: For cutaneous lesions only, the mean TTO utility values was 0.27. In other words the men were willing to trade a life expectancy of 5 years for a shorter period (1.4 years) in perfect health. More severe KS health states were rated lower (0.07 to 0.09). The mean rating scale value for cutaneous lesions only was 0.11 and ranged from -0.10 to -0.04 for the more severe conditions and were systematically lower than the TTO ($p=0.014$). A large overall potential gain in quality of life from treatment (partial response minus stable disease) was found for each condition for both the TTO (0.31 to 0.55) and the rating scale (0.38 to 0.44).

Conclusions: Respondents associate KS health states with extremely poor QoL and indicate that large gains are possible through modest treatment effects. While TTO returns higher values than the rating scale, potential gain from treatments were similar. The techniques appear suitable for application to QoL and economic evaluation of treatments of KS.

Key words: Kaposi's sarcoma, quality of life, economic evaluation, time trade-off.

The Use of Preference Techniques to Value the Health Gains from Treatment: Kaposi's Sarcoma

Introduction

Kaposi's sarcoma (KS) affects 30% of male AIDS patients. It may present initially as a few skin lesions but approximately half of the patients develop progressive disease that is associated with a very poor prognosis (median survival 6 months) [1]. There is no cure for AIDS-related KS but several therapies are available for palliation. Treatments are applied either locally or systemically. Radiation can be applied, but only to a few lesions at one time. Chemotherapy may also be administered, particularly for the severe progressive form of the disease [2]. While there has been a decline in the overall incidence of AIDS-related KS, for those who contract the disease not only is the prognosis poor but the many physical and psychosocial problems associated with the disease tend to profoundly affect a patient's quality of life [3]. The remaining months or years of survival are frequently marked by a poor quality of life attended by pain, functional impairment, cosmetic stigmata, central nervous system complications, loss of employment, poverty, ostracism, guilt, and anger. This psychosocial burden tends to disrupt the patient's efforts to deal with the disease [4].

There have been a number of new treatments for the condition developed in recent years. The apparent high unit cost of treatments such as the pegylated liposomal formulations of doxorubicin and daunorubicin or Interferon alpha-2b, means that consumers and third party payers need to be assured that treatment strategies are both effective and cost effective. In order to establish cost effectiveness, treatments need to demonstrate a significant improvement in quality of life in terms comparable with other alternative uses of health care resources. The preferred method of valuing changes in health related quality of life in the economic analysis of medical treatments is to use patient values of states of health associated with disease and its treatment [5]. A patient value or 'utility' is defined as the level of subjective satisfaction, distress, or desirability that people associate with a particular outcome [5, 6]. If it is expressed as a single value on a scale ranging from 0 (death) to 1 (perfect health), it can be used along with survival data to calculate quality adjusted life years (QALYs), a measure of outcome commonly used in the economic evaluation of health care [6]. The values that subjects attach to these states are called utilities of health states and have been commonly used in evaluating alternative treatments in clinical trials (e.g. standard care versus a new more toxic treatment with the expectation of longer life).

There are a number of methods of obtaining utility values but a common, relatively simple method is described as the Time trade-off (TTO) technique. Respondents are asked to state their preference between two health states – an unhealthy one for a fixed period of time (for example five years, followed by death), and a 'healthier' one accompanied by a shorter survival time. The individual makes hypothetical trade offs between improved health and shorter survival time. The length of time an individual is prepared to trade to be in the better health state is used to estimate the utility of that health state. An alternative and simpler technique is the use of a visual analogue scale, where respondents are asked to indicate on a line between 0 and 100 where they perceive particular health states should be placed. The scale is constrained at one end to be equal to best imaginable health, and lesser health states, including death, are placed on the rest of scale extending to zero. This technique has the advantage of simplicity and does not require specially trained interviewers. However, it is thought that simplicity leads to a lack of deliberation, less precise answers, and the scaling properties have been questioned [7, 8].

While there have been several Quality of Life (QoL) studies of HIV/AIDS [9] conducted, there are few data on the effect of KS on the QoL of sufferers. Quality of life issues in life threatening diseases where few effective treatments exist are becoming increasingly important and are facilitated by a growing number of generic and disease-specific health-related quality of life instruments suitable for cancer or HIV/AIDS research (reviewed by [9]). These instruments, however, tend to be too general to capture the specific features of AIDS-KS, furthermore they tend not to be capable of producing a single score on a life-death ratio scale needed for cost effectiveness analysis. These factors suggest the need to explore the use of study population-specific stated preference techniques such as the TTO and visual analogue scales in chronic severe diseases such as AIDS-KS.

It is an unresolved issue as to whose preferences should be used in a stated preference measure of health related quality of life [5]. If the ultimate purpose is to estimate the cost effectiveness of a treatment from a social perspective then it could be argued that the general public should be asked for their values. It may be that the general taxpaying population have a different view on the improvement in the quality of life from treatment than those who suffer from the disease. On the other hand the general public might not be well informed about the nature of the disease to state an informed preference. In this paper we examined differences between the value of quality of life with KS between those who have KS and those who are likely to be well informed about the disease but do not suffer from it.

The main aim of the paper is to explore the possibility of calculating individual preference-based values of quality of life for KS, and the potential differences in those values across techniques and patient groups. If successful, these techniques could be used to calculate values for new treatment outcomes and ultimately be used in calculating the cost per increase in quality adjusted life years from treatment, even where there is no survival gain.

Methods

Subjects

The subjects comprised a convenience sample of male volunteers who were HIV-positive diagnosed with Kaposi's Sarcoma (N=17) or free of KS (N=15) recruited by local Research Officers of the National Association of People Living with HIV/AIDS group, and the NSW AIDS Council/Gay Men's Health Centre. Anonymity of the men was maintained and no demographic data were obtained, although the age range was approximately 30 and 60 years. Interviews were held in the Aids Council (Sydney), the Centre for Health Program Evaluation (Melbourne) or in their own home. Interviews were conducted by trained interviewers who had experience with the techniques used. All respondents were reimbursed \$25 to cover travel expenses. The interviews lasted for about three-quarters of an hour. The research protocol was approved by the Victorian AIDS Council/Gay Men's Health Centre Research and Ethics Committee.

Interview methods

The techniques used to elicit preferences (utilities) were 'Time Trade-Off' (TTO) and a visual analogue scale [10]. For the TTO, participants are asked for their valuation of a *hypothetical* state 'A' relative to a *hypothetical* state 'B' in terms of their willingness to give up survival time in exchange for an improvement from 'A' for 5 years to 'B' for a shorter period of survival. The time ratio provides a relative preference weight, which is used to calculate the difference in quality

adjusted life years (QALYs) between treatments. This provides the denominator in the conventional incremental cost effectiveness ratio used in economic evaluation of therapies i.e. incremental cost per incremental quality adjusted life years [6]. The visual analogue scale asked individuals to place their rating of a health state on a line that ranged from 0 (death) and 100 (best imaginable health).

Definition of KS health states

The KS health states and treatment scenarios were developed through a structured process with the aid of experienced clinicians treating people suffering AIDS-KS. Four categories of HIV-KS were identified; (1) cutaneous lesions only, (2) cutaneous lesions and gastrointestinal disease, (3) cutaneous lesions and pulmonary disease, and (4) cutaneous lesions and nodal disease. *Cutaneous lesions* were described as dark purple/red lesions, slightly elevated, nodular or plaque-like. These lesions cause cosmetic anxieties, pain, and in areas where exposed to friction they can become ulcerated. Patients with facial lesions are often very concerned, because KS lesions are very readily recognised stigmata in the gay community. *Gastrointestinal disease* includes the presences of oral mucosal lesions that cause pain, and difficulty swallowing. Other important gastrointestinal manifestations include diarrhea, indigestion, griping abdominal pain, malabsorption, significant weight loss, and/or blood loss. *Pulmonary disease* was described as having shortness of breath, cough, chest pain, wheeze and haemoptysis. Other pulmonary associated symptoms include fatigue, poor exercise tolerance and low energy levels. *Lymph node* involvement included blockage of the circulation of lymph causing oedema of the upper or more commonly the lower limbs which may then significantly restrict mobility.

The likely therapeutic responses that occur through treatments were also elicited through expert opinion and included the following clinical categories: *Complete response* – the absence of any detectable residual disease, including tumour-associated oedema. For patients with pigmented macular skin lesions persisting after apparent complete response, one representative lesion must have been biopsied and documented free of malignant cells; *Clinical complete response* – no detectable residual disease including tumour-associated oedema but the patient has had no tissue biopsied; *Partial response* – no new lesions or new visceral sites of involvement and a 50% or greater decrease in the number of all previously existing lesions; *Stable disease* – any response not meeting the criteria for complete response, partial response or progressive disease; *Progressive disease* – new visceral and cutaneous sites of involvement or progression of existing disease.

Final health states descriptions were developed through an iterative process of review by clinicians and by men with HIV/AIDS who were members of the National Association of People Living with HIV/AIDS (see appendix). At the end of the process all individuals confirmed that the health states were a very good representation of the clinical presentations of the disease. For the purposes of the TTO and rating scales valuation of potential health gains, the vignettes of a *partial response* (i.e. 50% tumour reduction) and *stable disease* were selected as the most realistic and clearest descriptors of the disease and potential treatment outcomes and were used throughout.

Statistical analysis

The mean, standard deviation (sd), median and interquartile range (IQR) of the TTO and the visual analogue scale were calculated for each health state. The health gain from *stable or progressive disease* to a *partial response* was calculated as the difference between the

preference value between the two health states. Individual preference scores and difference scores tended not to be normally distributed for both metrics ($p < 0.01$ Kolmogorov-Smirnov test), so non-parametric tests were used.

The Wilcoxon signed ranks test was used to determine whether patient scores using the TTO were different to their scores obtained from the visual analogue scale. The Mann-Whitney U test was used to assess whether scores between groups (history of KS vs HIV only) were different.

Results

Time trade off (TTO) assessments

Table 1 shows the mean TTO utility values scored between 0 (death) and 1 (best imaginable health) for the four disease scenarios. The mean utility value for the whole sample for stable cutaneous lesions was 0.27 (median 0.15, IQR 0.00-0.73). In other words, on average respondents said that they were indifferent between living for 5 years with cutaneous lesions and living for only 1.4 years in best imaginable health. That is, they were willing to give up 3.6 years from a life expectancy of 5 years with stable disease if it meant that they could live in a state of best imaginable health. For those who had a history of AIDS-KS the mean value was lower at 0.23 (median 0.09, IQR 0.00-0.47). In other words these men were willing to give up 3.9 years of a life expectancy of 5 years if it meant that they could live in a state of best imaginable health for those 1.1 years. The mean value from the HIV only group was somewhat higher at 0.32 (median 0.17, IQR 0.00-0.77) suggesting that they did not consider Kaposi's sarcoma with cutaneous lesions to be quite as severe as the AIDS-KS group. Nevertheless a value of 0.32 still means that they would be willing to give up 3.4 years from a life expectancy of 5 years if they could live in the best imaginable health. There was no statistically significant difference in the value of cutaneous lesions between the groups.

Table 1 TTO absolute utility values for typical Kaposi sarcoma health states and potential health gains from treatments*

Disease scenario	History of AIDS-KS (n=17)				HIV only (n=15)			Total (n=32)				
	mean	median	IQR		mean	median	IQR	mean	median	IQR		
Cutaneous lesions only	0.23	0.09	0.00	0.47	0.32	0.17	0.00	0.77	0.27	0.15	0.00	0.73
partial response	0.63	0.77	0.39	0.86	0.54	0.69	0.09	0.86	0.59	0.71	0.13	0.86
health gain	0.40	0.69	-0.09	0.86	0.21	0.52	-0.69	0.86	0.31	0.56	-0.60	0.86
Cutaneous lesions and gastrointestinal disease	0.03	0.00	0.00	0.05	0.12	0.00	0.00	0.14	0.07	0.00	0.00	0.08
partial response	0.66	0.69	0.64	0.69	0.58	0.69	0.55	0.69	0.62	0.69	0.61	0.69
health gain	0.63	0.69	0.59	0.69	0.46	0.69	0.41	0.69	0.55	0.69	0.53	0.69
Cutaneous lesions and respiratory disease	0.10	0.00	0.00	0.10	0.09	0.00	0.00	0.07	0.09	0.00	0.00	0.10
partial response	0.59	0.69	0.59	0.69	0.60	0.69	0.62	0.69	0.60	0.69	0.59	0.69
health gain	0.50	0.69	0.48	0.69	0.51	0.69	0.55	0.69	0.50	0.69	0.48	0.69
Cutaneous lesions and nodal disease	0.05	0.00	0.00	0.10	0.14	0.00	0.00	0.28	0.09	0.00	0.00	0.14
partial response	0.64	0.69	0.59	0.69	0.55	0.69	0.41	0.69	0.60	0.69	0.55	0.69
health gain	0.58	0.69	0.48	0.69	0.41	0.69	0.14	0.69	0.50	0.69	0.41	0.69

* Health gain: The difference in utility between Cutaneous lesions only and a *partial response* from cutaneous lesions (see text for definition of partial response).
IQR: interquartile range

For all types of the more severe systemic stages of the disease, respondents were willing to give up an average of more than 4 years out of 5 years left, if they could live in a best imaginable health state rather than in a state of stable or progressive disease. A large proportion (44%) of the sample rated cutaneous lesions only as being equivalent to death (i.e. zero utility) and as expected, an even larger proportion rated the more serious forms of the disease at this level also; 75%, 69% and 63% for gastrointestinal, respiratory and nodal disease respectively.

The mean value for partial response to treatment for those with cutaneous lesions only was valued at 0.59 (median 0.71, IQR 0.13 – 0.86). In other words, respondents stated that they would be willing to give up 2 years of a 5 year survival if they could improve their quality of life from a "partial response to cutaneous disease" to best imaginable health. The mean values for partial response to treatment in the more severe disease states for the total population surveyed were all rated similarly, ranging from a mean of 0.59 to 0.62. In other words respondents were willing to give up about 3 years of a 5 year survival to have a partial response. There were no significant differences in the scores obtained from respondents with a history of AIDS-KS and those with no history of KS.

The absolute mean difference between preference values of stable disease and partial response health states (i.e. potential health gain through treatment) ranged between 0.31 (median 0.56, IQR -0.60-0.86) for the cutaneous lesions only group to 0.55 (median 0.69, IQR 0.53-0.69) for cutaneous lesions and gastrointestinal disease.

Rating scale values

Table 2 shows the results of the rating scale preference values for the health states transformed from the 0 to 100 scale where the value of death is rescaled to a value of (0.0) and best imaginable health (1.0). The absolute value for cutaneous lesions only was very low where the overall mean is 0.11, (median 0.21, IQR 0.03-0.33) i.e. 11% of best imaginable health for cutaneous disease alone, and close to zero (death) or below zero (worse than death) for the more severe forms of AIDS-KS.

Table 2 Mean adjusted 'Rating Scale' utility values for typical Kaposi sarcoma health states and potential health gains from treatments*

Disease scenario	History of AIDS-KS (n=17)				HIV only (n=15)				Total (n=32)			
	mean	median	IQR		mean	median	IQR		mean	median	IQR	
Cutaneous lesions only	0.17	0.20	0.00	0.35	0.04	0.25	0.11	0.30	0.11	0.21	0.03	0.33
partial response	0.60	0.60	0.49	0.78	0.45	0.75	0.50	0.79	0.53	0.72	0.50	0.78
health gain	0.43	0.35	0.21	0.54	0.42	0.47	0.30	0.60	0.42	0.40	0.23	0.57
Cutaneous lesions and gastrointestinal disease	0.00	0.00	-0.06	0.11	-0.09	0.06	-0.01	0.24	-0.04	0.03	-0.01	0.19
partial response	0.44	0.47	0.30	0.61	0.35	0.65	0.30	0.72	0.40	0.50	0.31	0.67
health gain	0.44	0.40	0.17	0.60	0.44	0.41	0.25	0.61	0.44	0.41	0.21	0.61
Cutaneous lesions and respiratory disease	-0.04	-0.05	-0.11	0.10	-0.14	0.05	-0.13	0.13	-0.09	0.00	-0.11	0.11
partial response	0.36	0.38	0.20	0.47	0.26	0.57	0.15	0.65	0.31	0.42	0.18	0.60
health gain	0.40	0.36	0.13	0.57	0.40	0.50	0.20	0.60	0.40	0.36	0.15	0.58
Cutaneous lesions and nodal disease	-0.05	-0.05	-0.15	0.07	-0.15	0.01	-0.13	0.20	-0.10	0.00	-0.14	0.11
partial response	0.31	0.20	0.05	0.57	0.24	0.50	0.13	0.67	0.28	0.41	0.11	0.61
health gain	0.37	0.29	0.14	0.58	0.39	0.40	0.20	0.53	0.38	0.32	0.17	0.56

* Health gain: The difference in utility between Cutaneous lesions only and a *partial response* from cutaneous lesions (see text for definition of partial response).
IQR: interquartile range

The partial response health states were rated much more highly than the stable disease states. The mean rating of a partial response to cutaneous lesions only was rated at 53% of best imaginable health (median 0.72, IQR 0.50-0.78), whereas the lowest rating for the more severe disease state was 28% for nodal disease (median 0.41, IQR 0.11-0.61).

Those respondents with a history of AIDS-KS rated the partial response to cutaneous lesions only at a mean of 60% (median 0.60, IQR 0.49-0.78) of best imaginable health. As expected, the more severe disease states were rated lower (from 31% to 44%). The HIV only group rated cutaneous lesions at 45% (median 0.75, IQR 0.50-0.79) of best imaginable health whereas the more severe systemic disease states were rated between 24% and 35%. There were no significant differences in the scores obtained from respondents with a history of AIDS-KS and those with no history of KS.

The absolute mean difference between preference values of each stable disease category and the corresponding partial response health state (or the potential health gain through treatment) were similarly rated and generally of the order of 0.37-0.44 independent of respondent group.

TTO and rating scale differences

Overall, the TTO method elicited higher utility scores than the rating scale for both the stable disease states (χ^2 11, df 3, $p = 0.014$) and for partial response disease states (χ^2 18, df 3, $p < 0.001$). Individual comparisons between TTO and the rating scale for stable conditions revealed that the difference was statistically significant only for cutaneous disease with nodal involvement (mean difference = 0.19; $Z = -3.0$, $p = 0.003$). For the partial response health states differences were evident for each of the more severe health states; gastrointestinal (mean difference = 0.22, $Z = -2.7$, $p = 0.006$), respiratory (mean difference = 0.28, $Z = -3.2$, $p = 0.001$) and nodal involvement (mean difference = 0.32, $Z = -3.0$, $p = 0.003$).

There were no overall differences between TTO and rating scale scores for the estimates of potential health gains. TTO tended to demonstrate slightly higher potential health gains for cutaneous lesions with gastrointestinal disease (mean difference = 0.11, $Z = -2.1$, $p = 0.04$) and cutaneous lesions with nodal disease (mean difference = 0.13, $Z = -2.2$, $p = 0.03$).

Discussion

This study has two important findings first for the treatment of KS and second for the choice of technique in the valuation of quality of life.

Treatment of KS

Respondents associate typical KS health states with extremely poor quality of life. Even for the least severe health state assessed (cutaneous lesions only) respondents reported utility values of 0.27 for the TTO method, in other words they were willing to trade a life expectancy of 5 years with the disease for a much shorter period (1.4 years) in perfect health, and 44% of subjects even rated this health state as being equivalent to death. For the more severe forms of KS, respondent's answers suggested they were willing to give up more than 4.5 years of an expected five-year survival with the disease for less than 6 months of perfect health, and more than two thirds rated the states as equivalent to death. When the rating scale method was used, even lower ratings were obtained. In other words both methods indicated that having to live with the

more severe forms of KS involves an extremely poor quality of life that for many respondents would be no better than death.

Treatment that provided even a partial response could dramatically improve the quality of life. This is true not just for those with more severe systemic disease but also for those who have only cutaneous lesions. The hypothetical treatment effect evaluated in this study was a *partial response*, that is, no new lesions or new visceral sites of involvement and a 50% or greater decrease in the number of all previously existing lesions. For respondents considering the condition cutaneous lesions only, a partial response led to a TTO utility shift from 0.27 to 0.59 (an increase in utility of 0.31).

Respondents scored health states systematically lower using the rating scale compared with the TTO. For example, the combined sample mean utility ascribed to cutaneous lesions only using the rating scale was 0.11 compared with 0.27 using the TTO. This difference of 16% translates to 10 months difference in the estimate of time respondents are willing to give up out of 5 years. The rating scale provides a lower estimate of the quality of life gain from treatment. The mean gain from partial response to cutaneous lesions, for example, for all groups using the rating scale is from 11% to 53% of full health. The comparable gain using the TTO is from 27% of full health to 86%. The difference is statistically significant. While systematic differences arise between the two utility elicitation methods, estimates of the magnitude of potential gain in QoL from treatments were not different. This suggests that while the absolute utility scores may be different between the methods, in this case the methods produce equivalent values of health change.

Valuation technique

The rating scale produces far lower relative values than the TTO method, but with wider interquartile ranges for the more severe health states. One confounding factor to bear in mind however is that, in the time trade off questions, where the respondent was unwilling to trade any time, a score of zero was recorded. As shown for the rating scale some respondents ranked stable or progressive AIDS-KS as worse than death. The TTO may be overestimating the value of severe AIDS-KS and understating the potential gains from treatment.

The fact that rating scales do show lower values is a well-recognised phenomenon and the literature suggests that the TTO is a more valid technique in eliciting patient values [6]. It should be recognised however that the absolute value of the partial response health states in the TTO method seems high in relation to the common observation that good health is rated around 80% of best imaginable in many studies of quality of life [11]. The respondents in our study appear to regard a partial response as better than most people regard good health. It may be that this is a health state indistinguishable from good health, or that given their underlying illness their health expectations are low and this influences their concept of the best imaginable health state. It has also been suggested more generally that those with experience of illness may give higher valuations to good health states [12]. Moreover our particular sample of individuals may have brought some strategic bias into the results. At the time of this research study there were a number of new treatments not yet subsidised by the Australian government. It may be that the respondents were part of a well-informed group of individuals, not only about the disease itself, but also the potential for new treatments. It is conceivable that some individuals assumed that the valuation exercise itself was part of a political decision process, and therefore provided artificially low values for the disease states in order to encourage public funding of a new treatment. However the time trade off exercise is not straightforward and one might expect strategic bias to show up as inconsistencies in responses.

These findings suggest that care must be taken when selecting the appropriate technique to estimate patient preferences and in the sample used for valuation. For example if the simpler and quicker rating scale method is chosen, it should be acknowledged that the values may be underestimates when compared with values obtained from the more complicated but more theoretically correct TTO method. As the current study suggests the TTO technique produces preference based health state values for KS that appear plausible. These could be used in a cost effectiveness study of treatment. The limitations of the present study however suggest that the results should be regarded as only illustrative of the potential of the use of stated preference techniques in eliciting individual preference based values for quality of life in the area of AIDS-KS. The actual values elicited could therefore only be used in an economic evaluation of treatment with caution.

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Appendix: Disease scenario descriptions of Kaposi Sarcoma health states

Disease Scenario 1 Cutaneous

- A** Your skin shows dark-coloured lesions on the face and torso that are unsightly and you feel reluctant to go outside or take part in your normal social activities
- B** Your skin shows pale flattened lesions which can be camouflaged with skin make-up. You feel able to go out and take part in your normal social activities

Disease Scenario 2 Gastrointestinal/Skin

- A** Your skin shows dark-colored lesions on the face and torso that are unsightly and you feel reluctant to go outside or take part in your normal social activities. You have raised lesions inside your mouth and throat that make eating difficult and painful. You have gripping abdominal pain, severe diarrhoea, weight loss, low energy levels and can eat only small amounts of certain foods at any time.
- B** Your skin shows pale flattened lesions which can be camouflaged with skin make-up. You feel able to go out and take part in your normal social activities. You have flat lesions inside your mouth and throat but these do not affect eating and you can eat most foods. You have occasional abdominal discomfort and diarrhoea but no weight loss

Disease Scenario 3 Pulmonary/Skin

- A** Your skin shows dark-coloured lesions on the face and torso that are unsightly and you feel reluctant to go outside or take part in your normal social activities. You have difficulty breathing and low energy, so that moving around is considerably restricted. You have a troublesome cough, chest tightness and wheeze. You have to sleep propped up on pillows and your sleep is often interrupted.
- B** Your skin shows pale flattened lesions which can be camouflaged with skin make-up. You feel able to go out and take part in your normal social activities. You are able to walk around but may experience some shortness of breath. You may have a cough and some chest discomfort. Breathing problems occasionally disturb your sleep.

Disease Scenario 4 Nodal/Skin

- A** Your skin shows dark-coloured lesions on the face and torso that are unsightly and you feel reluctant to go outside or take part in your normal social activities. Your legs and groin are extremely swollen and painful. Walking is extremely difficult for you
- B** Your skin shows pale flattened lesions which can be camouflaged with skin make-up. You feel able to go out and take part in your normal social activities. You may have a small amount of swelling in the groin and legs but you are able to walk.

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Centre for Health Program Evaluation

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