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**Meaning behind measurement: Self-comparisons affect responses to health related quality of life questionnaires.**

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## Introduction

Health Related Quality of Life (HRQOL) is accepted as an important outcome in the evaluation of health care interventions and treatments. The subjective nature of quality of life is pertinent to this area of study as most measures of assessment include self-reports. Questions are sometimes ambiguous and cover a wide range of health-related symptoms, particularly in generic, non-disease specific instruments. Thus, the researcher faces the challenge of gaining insight into the complex and ongoing cognitive processes engaged in by respondents when completing HRQOL questionnaires. This is an important challenge as respondents are likely to vary in the implicit reference frame comparisons they employ when evaluating their own HRQOL<sup>[1]</sup>. It is likely that this variation will affect responses to HRQOL items and lead to an incomplete understanding of the outcome under assessment.

A study conducted by Fayers et al.<sup>[2]</sup> found that the majority of questionnaire participants reported using reference frame comparisons when completing an annual HRQOL questionnaire. Only 33% of participants, however, reported using the same comparison reference frame at each yearly interval. No pattern was observed to explain the changes in reference frame choice. Reported reference frames were associated with effects of similar magnitude to the differences in HRQOL that are regarded as clinically important. The authors suggested that reference frame choice may be of particular concern in trials that randomise patients to management in different settings, such as treatment at home / in hospital, or surgery /chemotherapy, and might bias or obscure HRQOL differences.

It is therefore important to understand what the term 'quality of life' means to people and how this influences their interpretation of health-related quality of life questionnaires. The aims of this present qualitative study are:

1. To substantiate the supplementary questions used by Fayers et al.<sup>[2]</sup>.
2. To use cognitive interviewing techniques<sup>[3]</sup> to gain insight into how people evaluate their quality of life when completing a HRQOL questionnaire.

## **Methods**

### Study sample

Participants were drawn from a UK multicentre, randomised controlled trial of intensive bisphosphonate therapy versus symptomatic treatment in patients with Paget's disease (The PRISM Trial, ISRCTN12989577) <sup>[4]</sup>. Paget's disease is a chronic metabolic bone disorder characterised by increased bone turnover. In total, 1331 patients were enrolled in PRISM.

A group of 87 PRISM participants were invited to participate in this study. Patients were excluded if they were unable to speak English, had less than one year life expectancy, or had limited hearing ability. Purposive sampling was used to achieve maximum variation across:

- Age
- Gender
- Severity of Paget's disease, indicated by time since diagnosis, number of bones affected, bone pain and serum total alkaline phosphatase level.
- Years since recruitment to the trial
- SF-36 general health score
- Response to self-rated quality of life questionnaire items (see figure I).

Letters of invitation and study information leaflets were mailed to potential participants. Twenty-two people (25%) replied wishing to join the study. One person was subsequently excluded due to difficulty arranging an interview.

Written informed consent was obtained at the time of interview. Five participants were interviewed in consulting rooms within a hospital outpatient setting. The remainder were interviewed in their own homes. Two researchers (CR & SS) carried out the interviews. Taped interviews were transcribed, removing any personal identifying information.

### Ethical Approval

The study received multi-centre research ethics committee, relevant local research ethics committee and hospital trust approval.

## Questionnaires

All participants had previously completed an annual questionnaire as part of the PRISM trial containing validated health assessment instruments: EuroQoL (EQ-5D), measuring general health status <sup>[5]</sup>, the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36, v2) assessing overall health status and eight health domains <sup>[6]</sup>, and the Health Assessment Questionnaire (HAQ) Disability Index of the extent of functional ability <sup>[7]</sup>. Four supplementary quality of life questions, as described in Fayers et al <sup>[2]</sup> (see figure 1) were added after the SF-36 and before the HAQ. The first two items (B12, B13) used the same response options as items one and two of the SF-36 but asked about quality of life instead of health. These were followed by an open-response item (B14) and finally a more specific item about comparison reference frames (B15). Participants could tick one or more of the response options in B15 or use the text box to provide an open response. These supplementary questions were designed to assess reported quality of life and to probe the use of self-comparison reference frames.

Figure I. Supplementary Questions

**B12. How would you rate your quality of life during the past week?**

Excellent   Very Good   Good   Fair   Poor  
           

**B13. Compared to one year ago, how would you rate your quality of life in general now?**

Excellent   Very Good   Good   Fair   Poor  
           

**B14. We realise that different people have different things in mind when they answer questions about their 'quality of life'. What things were you thinking about when you assessed your quality of life?**

Please write your answers in this box

**B15. When you rated your overall quality of life, were you mainly:**

- Comparing yourself against before you became ill?
- Comparing yourself against how you felt one year ago?
- Comparing yourself against other people with Paget's disease?
- Comparing yourself against healthy people that you know (such as friends or family)?
- Or thinking of something else?

If you were thinking of something else, please tell us what it was:

Please write your answers in this box

## **Cognitive interviews**

The processes employed by respondents were investigated by interviewing participants who had previously completed a PRISM trial questionnaire (either at baseline or annual follow-up). The interviews were between 3-12 months after previous questionnaire assessment. Probes, e.g. 'can you tell me what you were thinking', were used to assist the respondents' reconstruction of the thought processes that may have been employed. Interviews were semi-structured with a pre-defined topic guide, which was intended to standardise the interview and minimise bias.

An interpretative phenomenological analysis approach was adopted. This is a qualitative technique in which participants' responses to a given phenomenon, in this case quality of life, are interpreted by the researcher along relevant themes. Participant responses were coded in a chart under theme headings. New themes were added to the analysis as they emerged from the interviews. Two members of the research team (CR, SS) independently coded responses under theme headings. Coding disagreements were resolved through discussions amongst the research team. The analysis was, therefore an iterative process, aimed at identifying a wide range of themes of importance to the participants. Sampling continued until no new information emerged from the interviews and data saturation was achieved <sup>[8]</sup>.

An example of how themes were arranged under topic headings is shown appendix I.

## **Results**

### Characteristics of Study Population

The sample comprised 21 participants, 11 men and 10 women, aged between 59–91 years, mean 63 years. Seven people had one bone affected by Paget's disease, 14 people had more than one bone affected, ranging from 2-7 bones (mean 3.5). Diagnosis of Paget's disease was 1-31 years previously, with a mean disease duration of 10.6 years. Other characteristics of the sample, chosen to successfully reflect the diversity of PRISM participants in line with our purposive sampling strategy, are described in Table I.

Table I. Selection criteria, demographics of the study population

	<b>n</b>
<b>Gender</b>	
Male	11
Female	10
<b>Marital Status</b>	
Single	2
Married	12
Divorced	2
Widowed	4
Other (Separated)	1
<b>Bone pain due to Paget's disease at last clinic (assessed by clinician)</b>	
Yes	12
No	8
Unsure	1
<b>Serum Total Alkaline Phosphatase level at last clinic</b>	
Low normal	7
Normal	6
Elevated	7
Greatly Elevated	1
<b>Bisphosphonate therapy in previous 4 months</b>	
Yes	4
No	17
<b>Years since recruitment to trial</b>	
Baseline	2
1 year	2
2 year	13
3 year	4
<b>Response to general health rating (SF36 item)</b>	
Excellent	2
Very good	2
Good	10
Fair	7
Poor	0
<b>Response to quality of life rating (questionnaire item B12)</b>	
Excellent	3
Very Good	4
Good	11
Fair	2
Poor	1
<b>Response to quality of life comparison against 1 year ago (questionnaire item B13)</b>	
Excellent	2
Very Good	5
Good	6
Fair	7
Poor	1
<b>Response to supplementary quality of life (questionnaire item B15)</b>	
Self-comparison before becoming ill	9
Self-comparison against 1 year ago	3
Comparison against other people with Paget's disease	0
Comparison against other healthy people	8
Something else	4

## Themes arising from cognitive interviewing

Table II shows the principal themes raised during the cognitive probing.

### Health Status

“Health” was discussed in relation to Paget’s disease and other conditions during the interview. People enjoying good health (n=10) described this as contributing to a good overall quality of life. Those in variable health (n=7) were also more satisfied with their quality of life than were people in poorer health (n=4). All participants stated that quality of life included factors other than health.

Three patients said that treatment for Paget’s disease improved quality of life, although the side effects of bisphosphonate medication negatively impacted on two people. Two people referred to using medical aids (such as hearing aids, shoe horns). This reference was made in the context of assisting quality of life, although the status of their overall health had reduced their quality of life. Two people described feeling dissatisfaction with their clinical treatment. This was discussed in reference to poor continuity of care if consultations occurred with numerous healthcare professionals, or occurred infrequently, defined as less than 3 physician appointments per year. One participant also expressed frustration that their treatment was orientated towards pain management rather than elimination of all symptoms.

Four people reported a reduction in energy levels. This was mentioned as impeding their ability to carry out or enjoy leisure activities, which caused irritation. This did not cause people to evaluate their quality of life as being poor. Rather, it was mentioned in relation to increased energy being desirable to improve quality of life.



Table II: Themes discussed during the interview

Theme Content	n
<b>1: Health Status</b>	
Good health	10
Poor health	4
Variable	7
<b>2: Pain</b>	
Pain not discussed	2
Pain discussed	19
Attributable pain discussed	15
Non-attributable pain discussed	4
<b>3: Mobility</b>	
Reduced mobility not discussed	6
Mobility reduction discussed	15
Difficulty walking discussed	15
Difficulty with basic activities discussed	9
<b>4: Emotional Impact of Paget's disease</b>	
Emotional impact not discussed	15
Emotional impact discussed	6
Loss of independence discussed	6
Frustration with physical limitations discussed	5
<b>5: Disease and/or Age Adjustment</b>	
Adjustment not discussed	4
Adjustment discussed	17
Disease adjustment discussed	12
Age adjustment discussed	7
Disease and age adjustment discussed together	2

## Pain

Presence of pain was a dominant theme, although the intensity of the pain described was variable. Discussion included general bodily pain as well as pain caused by Paget's disease. Where people experienced a lot of pain it was usually described in terms of its incapacitating effect on daily activities. One participant noted that presence of pain did not deter him from functioning as normal and therefore pain did not reduce quality of life. Furthermore, when we examined the self-rated quality of life scores for those participants who discussed pain, only two of the participants had rated their quality of life as 'Fair' while the rest had rated their quality of life as 'Good'.

Fifteen participants mentioned experiencing pain that was attributed to a physical activity, such as gardening or walking. This type of pain was expected and therefore manageable. Transient, non-attributable pain, however, was described as being particularly difficult to cope with, due to its unpredictability. Non-attributable pain also

gave concern to one participant who thought this was an indication that their Paget's disease was spreading to other areas of the skeleton.

Eight people reported analgesia usage to cope with their pain. All reluctantly accepted analgesia usage was necessary for coping with pain. The effect on quality of life was therefore contradictory. The pain relieving properties improved quality of life, but their use created feelings of personal dissatisfaction. Three people also discussed pain as reducing spousal and other relatives' quality of life. This was discussed both in terms of participants requiring help from their relatives or not being able to give help, such as acting as a carer for a spouse or being able to help children with babysitting.

### Mobility

Fifteen participants mentioned experiencing reduced mobility. The effect on quality of life greatly depended on how severely mobility was restricted. Mobility restriction was usually discussed in terms of reduced walking ability but also involved carrying out other basic activities such as dressing oneself, or the requirement of functional aids. Where participants faced difficulties in carrying out daily activities they often stated that they felt "lazy" for taking frequent rests or were dissatisfied with how they had completed the activity. Where participants' mobility allowed them to carry out daily activities to high or satisfactory levels, this was expressed with pride and was considered to be an achievement when taking their age into consideration. Keeping active was also mentioned as promoting mental fitness.

### Social Function

Twelve people discussed being physically able to maintain social contact as being important. Having regular contact and social interaction with one's immediate family, i.e. children and grandchildren, was considered especially important. Reduced mobility sometimes impeded the ability to socialise with friends or family and this negatively affected quality of life. Three people mentioned the support given by their spouse in terms of companionship and for physically engaging in social activities.

### Emotional Function

Six people described the emotional impact of Paget's disease. Loss of independence and spontaneity were the main cause of upset. Five participants mentioned feeling frustrated by their physical limitations, particularly in comparison to

previous activity levels. Three participants also felt that their disease limitations (e.g. slowness in walking, handling cutlery) had caused them public embarrassment. Attitudes towards these limitations affected them greatly. Participants stated that their family was a fundamental source of support when they required help due to a lack of mobility or physical strength. Four people felt that accepting help caused frustration at having to rely on others.

### Disease and Age Adjustment

The majority of participants discussed making cognitive adjustments, either consciously or unconsciously, to their perception of quality of life. This was described as changing the parameters for measuring a good standard of quality of life. Adjustments were made through acceptance of having a chronic disease, and accommodating symptoms so that quality of life was still judged as being favourable. For many this was achieved by adopting a 'positive outlook' through positive coping strategies and an optimistic approach to life. Eight people discussed how this approach had contributed to feeling 'happier' with their lives. In contrast, one participant stated that their declining health had negatively influenced their ability to have a positive outlook.

Seven people made reference to adjusting for age related limitations, such as experiencing general aches and reduced physical functioning. People who made reference to undergoing disease and/or age adjustment made more positive evaluations of their quality of life than those who made no reference to adjustment. Comparison between these two groups of people with the number of years they had been diagnosed with Paget's disease revealed no consistent pattern, suggesting that disease adjustment is not a function of time spent with the disease.

### Reference Frames

Participants were probed to discuss whether they had particular comparison groups or reference frames in mind when deciding how to rate their overall quality of life (Table 3). All participants confirmed that they had used at least one of the suggested self-comparisons, and of these seven stated during interview that they had more than one of the themes in mind, although only three of these had ticked more than 1 questionnaire option.

#### Self-comparison with 1 year ago

Eight participants described feeling a general decline in the last year, while two mentioned that they felt the same as they did one year ago. Participants discussed this reference frame as a comment on their health status during the interview rather than as an evaluation of their quality of life.

#### Self-comparison before becoming ill

Seven participants made this comparison, either with respect to a specific time in the past such as before retirement, or to the past in general. Discussion was in the context of a reduction in health or mobility. It was generally asserted that, although comparison with the past revealed a reduction in quality of life, this did not influence ratings of current quality of life.

#### Comparison with others with Paget's disease

Specific comparison with other people with Paget's disease was made by three participants. In each case, the participant felt that the comparator had more symptoms than themselves. One participant commented that they had so few symptoms that they didn't feel the need to make comparisons with other Paget's disease sufferers. Another person similarly mentioned that they would find it "depressing" to make such a comparison and that they did not give much consideration to their disease. Most participants, however, did not know anyone else with the condition.

#### Comparison with healthy people

Five respondents made comparisons with healthy people. Most felt that they were able to do as much, if not more as healthy people. One person acknowledged that they were not as physically fit as other healthy people. Healthy comparators included people known to the participants, for example friends or family, as well as other healthy people in general (age matched and younger).

#### Comparison with others of the same age

A majority (17) of participants acknowledged having compared themselves to age-related peers. This usually involved comparison with friends. Comparisons were usually favourable, either due to others' ill health or due to peers enjoying relatively good health for their age. Two people added the caveat that comparison with friends

may have been inaccurate as they could not be certain of the true nature of another person's health or quality of life, but that they had nonetheless been influenced by their perception of the health of these peers.

#### Comparison with other non-healthy people

Thirteen participants said they had contrasted themselves against other non-healthy people (i.e., not with Paget's disease), and this comparison included both non-healthy people known to the participants, and reference to non-healthy people in general. Where people compared themselves to other non-healthy people they always considered themselves to be in better health and with a higher standard of quality of life.

Table III: Reference frames

<b>Theme content</b>	<b>n</b>
Self-comparison 1 year ago	10
Self-comparison before becoming ill	7
Comparison with others with Paget's disease	3
Comparison with healthy people	5
Comparison with others of the same age	17
Comparison with other non-healthy people	13

#### Emergent Themes

In addition to the response categories provided in the questionnaire, novel themes emerged from the interviews. These are described below.

#### Transient Reference Frames n=8

Participants discussed changes in reference frames between questionnaire completion and interview. This occurred in the context of questionnaire completion during a 'bad week'. Pain was often a contributing factor to changes in reference frame comparison.

#### Interaction of Reference Frames n=7

Participants discussed using more than one reference frame during their evaluations (median = 2). Reference frames often interacted in complex ways, e.g. simultaneous comparison with healthy and non-healthy people. This made it difficult for participants to describe their personal reference frames. Interactions usually

involved comparison with self before becoming ill, healthy other and non-healthy other reference frames.

#### Difficulty Completing HRQOL Questionnaire n = 10

Ten participants stated that they found the questionnaire problematic. These people had difficulty rating quality of life due to the nebulous nature of the phenomenon. Confusion also centred on whether evaluations should focus on overall HRQOL or on the health condition under investigation only (n=3). For three participants, questionnaire items seemed irrelevant either to the participant or to trial aims. Participants picked the middle choice or 'happy medium' in this circumstance. All would have welcomed clearer instruction for completing the questionnaire.

### **Discussion**

The interviews highlighted many common themes. All participants stated that although their health was a consideration in evaluating quality of life, it was not the most important factor. This supports the observation that underlying health conditions do not consistently explain responses given in HRQOL questionnaires <sup>[9]</sup>.

Reduction in vitality was acknowledged as impacting on social functioning, particularly in reference to maintaining social relationships. Social interaction with friends, and particularly family members, was mentioned as being very important for quality of life. The benefits of having this type of support appear to be unrelated to the severity of disease, i.e. people with greater symptoms did not place a higher value on social relationships than those who had fewer symptoms.

Optimism emerged as being an important factor in quality of life evaluation. Participants who accepted the limitations resulting from increasing age and chronic disease were 'happier' with life. This is in keeping with Langston et al. <sup>[4]</sup> who reported that the wider PRISM population showed minimal evidence of impaired psychological health or depression, despite having a significantly reduced quality of life in physical functioning domains compared with the normal population. Engagement in disease adjustment was not associated with the severity of Paget's disease, as indicated at the patients' last clinic visit, or duration of disease. Thus, it would seem that there is not a consistent association between duration of disease and degree of adjustment. Rather adjustment for age and disease appeared to reflect a subjective determination to evaluate life within the reduced margins.

Adjustment was mainly described as being a conscious process that was deliberately adopted. In contrast some people noted that they had come to terms with the changes caused by age and disease automatically and only noticed limitations when they had cause to reflect on the past. This is consistent with previous theories of stability of self and homeostatic regulation of subjective well-being whereby a previous level of subjective well-being is returned to through the process of cognitive bias when an external threat to self-satisfaction is encountered <sup>[10-13]</sup>. Only one participant considered their health to have negatively impacted on outlook. In other cases where participants tended to be less optimistic this was due to factors unrelated to their health. This demonstrates the subjectivity involved in the evaluation of quality of life and proves the difficulty in comparing people using generic quality of life rating scores.

It was evident that participants engaged in both downward and upward social comparisons when completing questionnaire items. This reinforces the hypothesis that people use comparison with others as a framework for shaping one's own expectations <sup>[1, 2, 14-20]</sup>. Interestingly the participant scoring 'poor' on the SF36 item engaged in self-comparison one year ago and before becoming ill. Comparisons were both explicit, based on own experiences with others, and implicit, based on general perceptions and beliefs. Reference frames also changed over time and interacted in complex ways, thus supporting our quantitative findings <sup>[2]</sup> and providing further evidence for the validity of using the supplementary HRQOL questions. This also supports the argument that subjective reference frames may create potential bias when HRQOL self-ratings are used in clinical trials or longitudinal studies <sup>[2]</sup>.

The current study findings are limited given the small sample size, the particular disease group and the narrow age range of the participants. The presence of the interviewer may also have introduced bias during the interviews, although it is hoped that this has been minimised as far as possible by the use of a topic guide to provide a standardised interview format. Due to the time required for arranging interviews following questionnaire completion, the interviews were conducted several months after the patients had completed the study questionnaires, including the supplementary questions, and so it is unclear to what extent the responses represented the thought processes used at that time, or whether current, and newer, views were being reflected; it would be interesting for a future study to use think aloud techniques concurrently with questionnaire completion. This approach is challenging for many respondents, however, and may not be suitable for an elderly

population. Further work could investigate the cognitive processes involved for those who have poorer self-reported health, for patients with other diagnoses, and for those with newly diagnosed illness. It would also be interesting to compare what themes are important in the evaluation of quality of life among a healthy population to examine how the perception of quality of life is influenced by the presence of a health complaint. The current findings, however, represent an insight into how people with disease evaluate their quality of life.

## **Conclusions**

The findings of this study demonstrate that the underlying health condition does not consistently explain HRQOL responses. By uncovering the meanings people attach to their HRQOL scores we showed that choice of reference frame varies between and even within patients, and this influences self-reported quality of life. This provides support for the quantitative results described in Fayers et al <sup>[2]</sup>. We conclude that uncovering the meanings people attach to psychometrically sound measures of quality of life can assist in refining the accuracy and precision of future quality of life assessment tools. Specifically, we suggest that the inclusion of supplementary questions in HRQOL questionnaires is useful to identify the self-comparison reference frames that could bias or obscure results. Specifying a particular reference frame for completing HRQOL questionnaires could further reduce ambiguity and aid measurement precision.

Importantly, half of the participants expressed uncertainty about the meaning or intention of the question about HRQOL, and stated that they would welcome clearer instructions for completing the questionnaires. We recommend that studies assessing HRQOL should explicitly state whether self-assessments should relate to overall quality of life, general HRQOL, or disease-specific HRQOL. Clearer wording of items to clarify whether respondents should consider their index condition only or all health problems would be beneficial.

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investigators who worked on the PRISM trial. We hope this paper will provide Paget's disease physicians with an insight into the meanings attached to quality of life for their patients.

### **Conflicts of Interest**

Anne L Langston has received a travel bursary from the Alliance for Better Bone Health; William D Fraser acts as a consultant for Procter & Gamble, MSD, Novartis, Sanofi Aventis, Nycomed and Roche; Peter L Selby acts as a consultant for Procter & Gamble, Novartis, Nycomed and Roche; Stuart H Ralston acts as a consultant for Procter& Gamble, Sanofi Aventis, and Novartis.

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Appendix I. Example of thematic arrangement of interview data by topic heading

<b>Biomedical</b>	<u>Co-morbid Conditions</u>	<u>Pain</u>	<u>Family/Spouse's Health</u>
	(index condition, other constraints, etc) <i>It's just this disease that has affected my right leg and my pelvis and it's quite limiting.</i>	(attributable pain, non-attributable pain, analgesia useage, etc) <i>it is just whether I am feeling pain or not.</i>	(impact of own health on spouse, impact of spouses' health on self) <i>My wife is rushing her shopping because she doesn't want me standing about suffering pain and agony. So it is affecting her as well, all these sort of things come into this</i>
<b>Functional</b>	<b>Basic Activities</b>	<b>Instrumental Activites</b>	<b>Mobility</b>
	(feeding, bathing, dressing, etc) <i>I have to get down or roll down on the floor to get things and you know putting shoes and stockings on and that sort of thing, you're limited to what I could do beforehand</i>	(shopping, housework, gardening, leisure, etc) <i>I will Hoover the bathroom and then I'm sore, I have to stop</i> <i>And I can't shop the same, .. I manage one shop and then sometimes I don't even manage my shopping there. I have to go home because I am walking two or three yards and I have to stop</i>	(physical limitations, affect on self/others, pain, etc) <i>I would have to stop about twice on the way down and then I would have to stop about three times and then it got that I wasn't able to walk it, I was having to stop</i>
<b>Psychological</b>	<b>Cognitive Status</b>	<b>Adjustment</b>	<b>Outlook</b>
	(intellectual function, specific dysfunction, e.g. memory problems, etc) <i>my ability to memorise and to recall, these are the important things to me.</i>	(age, disease, self-imposed norms, etc) <i>if you say to me do you expect your health to decline, right away I'm going to say yes because I'm getting older, it's bound to decline</i>	(positive, negative) <i>It's how you're prepared to accept anything that's wrong with you</i>
<b>Social</b>	<b>Support Network</b>	<b>Leisure</b>	<b>Civic Standing</b>
	(spouse, family, friends, acceptance of	<b>Activities/Hobbies</b> (Group activities, physical	(committee/organisation membership, helping

<p><b>Frame of Reference</b></p>	<p>help, etc)</p> <p><i>My family looks after me, I have three good sons, so I am quite well off really</i></p> <p><i>Well, quality of life is having a happy life, I have a lovely family</i></p> <p><b>Treatment Representations</b></p> <p>(satisfaction with health professionals, perceived norms of health professionals, etc)</p> <p><i>My treatment, well what am I going to say, the treatment I get is flaming awful or it doesn't exist. What treatment can you give except painkillers</i></p>	<p>limitations, contact with friends/family, etc)</p> <p><i>Well you see we are in a fun club, we have drives, we always go away</i></p> <p><b>Illness Representations</b></p> <p>(comparison self, comparison others, etc)</p> <p><i>Well I suppose I enjoyed living the way I was when I was fit and so that's the marker</i></p> <p><i>When I say that I do so much more than some people that haven't got Paget's, there is nothing wrong with me</i></p>	<p>community, etc)</p> <p><i>Being a member of the [organisation] I do a lot of research work, so I give lectures on the subject, and it depends on how well I have been doing there</i></p> <p><b>Questionnaire Completion</b></p> <p>('good' or 'bad' week, etc)</p> <p><i>Well, I must have thought I'd a good week and that last week was excellent</i></p>
<p><b>Questionnaire Issues</b></p>	<p><b>Questionnaire Completion</b></p> <p>(easy/difficult to complete, etc)</p> <p><i>It's made out for everybody. Anybody could understand it and it's simple enough to adapt to your own needs</i></p> <p><i>I think it could have been difficult if you put too much thought into it</i></p>	<p><b>Understanding</b></p> <p>(easy/difficult to understand purpose of questionnaire, etc)</p> <p><i>if you are wanting to know the answer to whether it's only on the health side or on the psychological side it's very difficult to draw a line.</i></p> <p><i>Well I mean there were sometimes I wondered what you meant by that, whether you were talking about just Paget's disease or whether you were talking about life in general or what, you know, but so we came to the conclusion that we would take the happy medium side of it</i></p>	<p><b>Amendments/Comments</b></p>