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Implicit self-comparisons against others could bias quality of life assessments

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on behalf of the PRISM trial group

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Abstract

Objectives: To explore how patient-reported health-related quality of life (HRQL) and global health status are affected by use of differing personal reference frames. We hypothesized that implicit comparisons against self at an earlier time, against healthy peers, or against ill patients would greatly affect patients' response values.

Study Design and Setting: Patients in a randomized trial for treatment of Paget's disease completed annual HRQL questionnaires. Supplementary questions were appended, asking the patients whether they were aware of having made implicit comparisons.

Results: The majority of patients reported considering themselves a year ago (31% at baseline), themselves before becoming ill (23%), or other healthy people (24%), with similar proportions during follow-up. Mean HRQL scores varied substantially according to the declared frame of reference, with differences as big as 19% of the scale score, or a standardized mean effect size of 0.74 standard deviations.

Conclusion: Reported reference frames were associated with effects of similar magnitude to the differences in HRQL that are regarded as clinically important. This may be of particular concern in trials that randomize patients to management in different settings, such as treatment at home/in hospital, or surgery/chemotherapy and might bias or obscure HRQL differences.

Keywords: Quality of life; Self-reported health; Self-rated health; Patient-reported outcomes; Reference frames; Response shift

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1. Introduction

Patient-completed global questions about "overall health" and "overall quality of life" (health-related quality of life, HRQL) have been reported to be important prognostic indicators in advanced cancer and are good predictors of survival [1,2], and similar results have been observed both for HRQL and for self-rated health in many other serious illnesses [3,4]. Furthermore, as Fayers and Sprangers noted [5], these results are curiously robust across a wide range of seemingly vague and nonspecific questions. Thus it is not at all clear what patients have in mind when they respond to such questions as "What is your overall quality of life during the past week?" Indeed, this seemingly simple question begs the query: "Compared to what?" Fayers and Sprangers speculated that patients might use different frames of reference, resulting in responses that are derived from implicit comparisons with various peer groups or against themselves at some previous time. Comparison groups that patients may have in mind include healthy people, such as friends or family; other patients ("Compared to all those other very ill patients I see at the clinic, I'm doing very well"); themselves prior to their illness; or themselves at some other previous time such as a year or more ago.

The aims of this study were to explore whether patients use identifiable frames of reference, and the impact these might have on responses to questions about well being or quality of life. We hypothesized that most patients would consciously have in mind one (or more) reference frames, and that these could be elicited by questioning.

Identifying these implicit comparisons is important because the response levels are likely to be affected by the particular comparisons used by each patient. We postulated that ill patients who are comparing themselves against a peer group comprising healthy friends would report a relatively poor HRQL, and that those who use other patients as their reference frame would report a better HRQL.

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2. Methods

2.1. Patients

A convenience sample was obtained from the ongoing PRISM randomized clinical trial of intensive versus symptomatic management for patients with Paget's disease (ISRCTN 12989577). Patients were already completing annually the SF36 (Medical Outcomes Trust Short-Form 36 Health Survey, version 2), the EQ5D (EuroQoL 5-dimension questionnaire), and the HAQ (Health Assessment Questionnaires). For our supplementary study, three additional questions were inserted after the SF36 questionnaire. As this was an opportunistic study, some trial patients had been recruited before the additional items were included. The trial recruited 1,325 eligible patients, of whom 976 completed the additional items at baseline (prerandomization), 1,076 at 1 year, and 967 at 2 years.

Severity of illness was assessed as time since the initial diagnosis, the number of bones involved, the level of deformity, and the number of fractures.

2.2. Questionnaires

The SF36 asks about "health in general" and offers response options from 1 = excellent to 5 = poor. We appended at the end of the SF36 an equivalent item, with the same response options: "How would you rate your overall quality of life during the past week?" Patients were then given an open-response question: "We realize 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?" Finally they were asked: "When you rated your overall quality of life, were you mainly comparing yourself against one or more of the following?" with options that included "before you became ill," "how you felt a year ago," "other people with Paget's disease," "healthy people that you know (such as family or friends)," and "something else (please specify)." Patients could tick one or more response options. The use of these additional questions was approved by the multicentre and local research ethics committees.

2.3. Statistical analysis

Patients were assigned to groups according to their self-reported reference frame. One-way analysis of variance (ANOVA) was used to test for differences between the groups. Effects were compared visually and plotted with 95% confidence intervals (CI). The study sample size had been determined for the main clinical trials outcomes and was easily large enough for this exploratory quality of life substudy. *P*-values are uncorrected for multiplicity of testing, and therefore, interpreted conservatively. Regression modeling was used to explore potential explanatory factors (age, gender, age at diagnosis, and disease severity as measured by bone deformity and bone pain, and HAQ scores). Patterns of change over time were explored by considering the transition matrices: for example, 26 patients reported using healthy peers at baseline and self before ill at 1 year, with mean change in HRQL of 0.27, whereas 22 changed in the corresponding reverse direction with a mean change also of 0.27. Generalized estimating equations (GEE) that can allow for correlations between successive ratings were also used to explore patterns of change over the three time points.

3. Results

The mean age of the patients was 74 (range 37–94), and 53% were male. Approximately 14% were recruited within the first year after diagnosis, and 50% were within 5 years of diagnosis.

Table 1 shows the distribution of the responses to the reference frame question, and the corresponding mean quality of life scores. At all time points, about 20% of patients said they had in mind how they were before they became ill, nearly a third were considering themselves a year or more previously, and about 20% were comparing themselves with healthy peers. There was also a gradual increase over time in the number of patients saying they were thinking of multiple references, reaching 19% by 2 years.

Table 1
Mean quality of life during the past week, by reference frame

	Baseline				1 yr				2 yr			
	Patients		Quality of life		Patients		Quality of life		Patients		Quality of life	
Reference frame	*N*	%	Mean	SD	*N*	%	Mean	SD	*N*	%	Mean	SD
Self, before ill	225	23	3.52	0.99	203	19	3.59	0.88	174	18	3.66	0.95
Self, 1 year ago	306	31	3.12	0.97	345	32	3.23	0.92	288	30	3.26	0.95
Healthy peers	239	24	2.77	1.09	200	19	2.87	1.07	189	19	2.83	1.00
Other Paget's patients	24	2	2.67	0.70	41	4	2.66	0.91	37	4	2.81	0.88
Something else	77	8	2.92	1.14	71	7	3.00	1.08	70	7	3.00	0.98
Multiple reference frames	84	9	3.45	0.95	187	17	3.52	1.00	185	19	3.45	1.00
No response	21	2	3.29	1.06	29	3	3.24	1.02	24	3	3.17	0.92
Total	976	100	3.13	1.05	1076	100	3.24	1.01	967	100	3.25	1.01
ANOVA *P*-values				<0.0001				<0.0001				<0.0001