VALUE IN HEALTH 18 (2015) 44–51

Available online at www.sciencedirect.com

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journal homepage: www.elsevier.com/locate/jval

Measuring Health-Related Quality of Life by Experiences: The Experience Sampling Method

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ABSTRACT

Objective: To explore the potential value of obtaining momentary, instead of retrospective, accounts of the description and valuation of a person's own health-related quality of life (HRQOL). **Methods:** Momentary HRQOL was examined with the experience sampling method (ESM) in 139 participants from four different samples. The ESM consists of a so-called beep questionnaire that was administered 10 times a day by an electronic device. Feasibility was determined by assessing willingness to participate in the study and by analyzing the percentage of dropouts and the number of completed beep questionnaires. Multilevel analysis was used to investigate the relation between momentary HRQOL and momentary feelings and symptoms. The relation between momentary outcomes and the EuroQol visual analogue scale was investigated with a multiple regression model. **Results:** The overall participation rate was low, but there were no dropouts and the number of completed beeps was comparable to that in other studies. Multilevel analysis showed that feelings and symptoms were significant predictors of momentary HRQOL. The strength of these relations differed among three patient groups and a population-based sample. The EuroQol visual analogue scale was not predicted by momentary feelings and symptoms. **Conclusions:** We can conclude that the use of the ESM to measure accounts of the momentary experience of health in different populations is feasible. Retrospective measures may provide a biased account of the impact of health problems in the daily lives of people who are affected. Moreover, the bias may be different in different conditions.

Keywords: *health-related quality of life, experience sampling method, preferences, utility measurement.*

Introduction

The quantification of the subjective experience of health-related quality of life (HRQOL) is crucial to the evaluation of health care technologies. HRQOL has been defined as an individual's perception of his or her physical health, psychological state, level of independence, social relationships, and relationship to the environment [1]. To assign meaningful numbers to HRQOL outcomes, the experience needs to be described in terms of severity and assigned a value. Instruments to obtain patient descriptions and valuations of their own health, such as the EuroQol 5D (EuroQol five-dimensional questionnaire) health description and the EuroQol visual analogue scale (EQ-VAS), rely on retrospective self-report. One problem with retrospective self-report is that it is likely to give a biased account of real-world experiences due to imperfect recollection of past experiences [2,3]. In other words, it only partially captures the impact of health problems in the daily lives of people who are affected. An alternative to retrospective self-report is to study outcomes from moment to moment in the context of daily life. The objective of the present study was to explore the potential value of obtaining momentary, instead of retrospective, accounts of the description and valuation of a person's own HRQOL. In this study, we focus on the physical and psychological dimensions of HRQOL.

Retrospective versus Momentary Self-Report

Robinson and Clore [4] reviewed several studies describing discrepancies between momentary and retrospective self-reports. Retrospective self-reports are less than perfect reflections of

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1098-3015$36.00 – see front matter

http://dx.doi.org/10.1016/j.jval.2014.10.003

experience because feelings are not always accurately represented in memory. If not measured directly, affective experience needs to be reconstructed on the basis of episodic or semantic memory. *Episodic memory* is the recollection of past personal experiences that occurred at a particular time and space. With regard to episodic memory, Kahneman [5] and Kahneman et al. [6] found that more memorable details of an emotional event disproportionately affect retrospective estimates of emotion. Also, there is a gradual decline in episodic memory over time [7], which leads to a reliance on semantic memory to fill in the memory gap of hedonic experience.

Semantic memory is a more structured record of facts and knowledge about the external world and relies more on generalized beliefs than on experiences. In this regard, there is a distinction between retrospective self-reports of global concepts and retrospective self-reports of specific feelings and symptoms. Global reports of past health will rely more on semantic memory, whereas reports on specific feelings and symptoms may more easily be recovered by detailed episodic recall [4,8,9]. As a result, the retrospective global valuation of health may be more prone to bias than the retrospective description of detailed aspects of health such as specific feelings or symptoms, a problem that increases with temporal delay [10]. More fundamentally, there is an increasing awareness that experiences are dynamic, situated, and highly context driven (see the contributions in Mesquita et al. [11]), thereby providing a powerful rationale for investigating experiences in the context in which they occur [12]. Moreover, bias in retrospective self-report might be different in different patient populations. For instance, depression has been shown to have an effect on memory performance [13,14]. As a result, a higher discrepancy between retrospective self-report and actual experiences may occur in persons suffering from psychological complaints. Furthermore, people do not adapt well to noise [15,16]. As a result, patients with a complaint such as tinnitus, which is the experience of a sound without an acoustic source, might disproportionately focus on this aspect when evaluating their HRQOL retrospectively.

Experience Sampling Method

In the present study, we used the experience sampling method (ESM) [17] to obtain momentary accounts of feelings, physical symptoms (PS), and HRQOL. The ESM is characterized by the collection of multiple self-reports of an individual's (near) real-time feelings, thoughts, and activities in real-world environments. ESM studies are conducted using paper diaries or (increasingly) electronic devices [18]. These devices beep at random moments, when participants are asked to complete a questionnaire. A potential limitation of the ESM is that it can be time consuming and intrusive, and as a result burdensome to participants [19].

Objectives

In this study, first, we assessed the feasibility of using the ESM to obtain accounts of the momentary valuation of HRQOL in different patient populations. Next, it was expected that if the momentary valuation of HRQOL would vary over time, this would be an indication that the momentary valuation of a global concept such as HRQOL is influenced by the momentary experience of more specific feelings and symptoms. Therefore, we assessed whether the momentary valuation of HRQOL is variable from moment to moment within persons. Furthermore, we examined the relation between momentary accounts of specific feelings and symptoms and the momentary valuation of HRQOL. Finally, we examined the relation between the global *retrospective* valuation of HRQOL (as obtained by the EQ-VAS) and the momentary accounts of feelings and symptoms and valuation of HRQOL.

Methods

Study Population

The study population consisted of 139 participants. To ensure a variety of experienced health states in the study population, participants were recruited from three patient groups—experiencing somatic complaints with a known cause (atherosclerosis or venous insufficiency), somatic complaints without a known cause (tinnitus), and psychological complaints (anxious or depressed)—and a population- based sample. All participants were 18 years or older. Exclusion criteria were not being able to read and write in Dutch or not being able to handle the electronic ESM device because of impaired motor skills (for more details, see Appendix A in Supplemental Materials found at http://dx.doi.org/10.1016/j.jval.2014.10.003).

Measures

ESM using the Maastricht routine [20]

The ESM consists of a beep questionnaire that participants are required to fill out at several unpredictable moments during the day, in addition to questions in the morning, on waking and in the evening when going to sleep. The validity and reliability of the Maastricht routine has been documented elsewhere [20]. In this study, we used the PsyMate, a small user-friendly device programmed to generate beeps (and vibrations) 10 times a day between 07.30 h and 22.30 h randomly in 1½-hour intervals. At every beep, the PsyMate presents the questions and records the responses using a touchscreen keyboard. The beep questionnaire (see Appendix B in Supplemental Materials found at http://dx.doi.org/10.1016/j.jval.2014.10.003) consists of items on feelings, physical symptoms, context (location, interaction, activities), and overall HRQOL. For the items on feelings—six for positive affect (PA) and five for negative affect (NA) and PS (four items)—a seven-point Likert scale was used. The contextual items had predetermined answering categories. To obtain a valuation of momentary HRQOL, a VAS anchored in the same way as the EQ-VAS (0 being the worst imaginable health state and 100 being the best imaginable health state) was included [21]. A detailed description can be found in Appendix A.

A global retrospective valuation of health, or HRQOL, was obtained using the EQ-VAS. The EQ-VAS is part of the EuroQol instrument, and it ranges from 0 (worst imaginable health state) to 100 (best imaginable health state). The EQ-VAS has good reliability [21].

Anxiety and depression was measured with the Hospital Anxiety and Depression Scale (HADS), which contains 14 items and has good reliability and validity [22]. Each item on the questionnaire is scored on a scale of 0 to 3, with 3 indicating higher symptom frequencies. In addition, data on personal characteristics were collected.

Procedures

The study consisted of three phases planned individually for each participant. All participants received €25 for their participation.

Briefing

During the briefing (approximately 3 hours) on the first day, the rationale of the study was explained and an instruction on the use of the PsyMate was given. A try-out sampling moment was simulated in which the participants were coached in answering the questions on the PsyMate. After the try-out baseline, global data were collected (the EQ-VAS, the HADS, and personal characteristics).