Understanding changes in quality of life in cancer patients: a cognitive interview approach
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CHAPTER 7

General discussion
The overall aim of this study was to increase our understanding of how cancer patients arrive at quality of life (change) assessments, and how to interpret such (change) assessments. To that end, we qualitatively examined the cognitive processes underlying cancer patients’ QoL (change) assessments in three designs commonly used in the context of treatment evaluation, i.e. the baseline-follow up or pretest-posttest design, the retrospective pretest-posttest or thentest design, and the transition design. Specific objectives were to examine the assumptions inherent to these designs. In this chapter, we will address and discuss the main findings, followed by reflections on this study’s methodology. Additionally, we will provide implications and directions for research, and implications for clinical practice.

7.1. Review on patients’ self-nominated QoL domains

7.1.1. Which domains do patients nominate as constituting their QoL?
Several studies examined the first cognitive process of the frameworks of Tourangeau et al. [1] and Rapkin & Schwartz [2] in addressing somatically ill persons’ self-nominated QoL domains. We therefore reviewed the extant literature (see Chapter 2). We conducted two literature searches in three different databases for studies using (1) the Schedule for Evaluation of Individual Quality of Life (SEIQoL) [3, 4], and (2) study-specific questions, which yielded 36 eligible papers. Since the method of enquiry might generate different QoL domains, we compared the QoL domains elicited in studies using the SEIQoL with those elicited in studies using study-specific questions. To that end, we first categorized all QoL domains presented in the selected papers according to the nine domains included in the SEIQoL prompt list. QoL domains that could not be grouped according to the SEIQoL prompt list domains were categorized in additional, inductively generated, domains. As expected, SEIQoL studies more frequently reported the domains used in the SEIQoL prompt list, whereas studies using study-specific questions more often presented the inductively generated domains. Nonetheless, most QoL domains were presented in both types of studies, albeit with different frequencies. Irrespective of the method of enquiry, all studies reported a domain referring to ‘health’. Conversely, only SEIQoL studies presented the domains marriage/spousal welfare, activity/mobility and sexuality. Interestingly, the inductively generated QoL domain ‘independence’, which is not included in the SEIQoL prompt list, was more frequently reported in studies using the SEIQoL than several other domains that feature in the prompt list. ‘Independence’ might thus be a suitable candidate domain to add to the SEIQoL prompt list.

7.1.2. Reflections on reviewing patients’ self-nominated QoL domains and directions for future research
In conducting this review, we had underestimated the effort it would take to provide a comprehensive overview of qualitative material. Most importantly, the different levels of abstraction and aggregation of QoL domains per study severely hampered cross-study
comparisons. To illustrate, we do not know whether QoL domains presented in each study are actually nominated by the patients themselves or rather represent an aggregation made by the researchers. For example, did patients themselves mention the QoL domain ‘health’ or is this an abstraction of the domain ‘feeling physically well’? In addition, comparing the presented QoL domains yielded interpretative difficulties. Can different QoL domains be considered synonymous or do they mean different things, for example ‘marriage’ versus ‘spouse’? In addition, limitations of the included studies and limitations inherent to the review process further impeded a comprehensive review. Although not originally intended, this literature study came to focus on important methodological aspects related to the generation of generalizable, qualitative data across conditions and from different methods of enquiry. Some of these issues concern shortcomings of qualitative studies that are amenable for improvement. To address these shortcomings we presented guidelines for conducting and reporting qualitative research aimed at exploring respondents’ self-nominated QoL domains [5]. These guidelines were targeted at a more comprehensive description of the sample, data collection procedure, analysis, and results. With respect to future research, it would be interesting to examine the extent to which widely used patient-reported outcome measures actually capture the relevant QoL domains as presented in this review.

### 7.2. Do theoretical models capture the cognitive processes underlying QoL assessment?

#### 7.2.1. Development of a comprehensive analysis scheme

We have operationalized patients’ cognitive processes according to the models of Tourangeau et al. [1] and Rapkin & Schwartz [2], resulting in five distinct cognitive processes: (1) comprehension/frame of reference, (2) retrieval/sampling strategy; (3) standards of comparison; (4) judgment/combinatory algorithm, and (5) reporting and response selection. These models combined proved feasible in describing the cognitive processes cancer patients use in answering QoL items (see Chapter 3) [6]. Not only were the patients capable of verbalizing their cognitive processes used in answering the QoL items, they were also found to pass through these cognitive processes more or less spontaneously. According to the models, overlap was found between the cognitive processes retrieval/sampling strategy; standards of comparison and judgment/combinatory algorithm in coding the interviews. To fully capture patients’ cognitive processes, we needed to extend the cognitive process ‘reporting and response selection’ with three editing processes: ‘self-protection’, ‘self-presentation’ and ‘normalization’. Tourangeau et al. [1] did propose processes aimed at editing an initial response in order to provide a socially desirable answer. However, the use of processes to edit a response for self-protection, self-presentation, and normalization is aimed at making an initial response acceptable for the respondent him/herself. The selected QoL items might have confronted the patients in this study with their deteriorating health, which is a likely explanation of their use of these editing processes. Since self-presentation
was also reported in a qualitative study by Westerman et al. [7] as affecting the response strategies of cancer patients' assessment of fatigue, it is likely that our additional editing processes are a useful supplement to the cognitive process reporting and response selection of the Tourangeau model.

In conclusion, the theoretical models of Tourangeau et al. [1] and Rapkin & Schwartz [2] adequately capture the cognitive processes that patients use in assessing (change in) their QoL. Moreover, our analysis scheme based on these models proved applicable in the analysis of these cognitive processes, and has been made publicly available for use in future studies [6].

7.2.2. Reflections on the a priori selection of theoretical models

The a priori selection of the cognitive process models of Tourangeau et al. [1] and Rapkin & Schwartz [2] as this study’s framework can be considered both a solid theoretical underpinning and a limitation. In contrast to conducting open and exploratory interviews, and solely analyzing our data inductively, we have used these models to elicit cancer patients’ cognitive processes and to guide the analysis of our data. Moreover, it is likely that knowledge of the two models have influenced the collection of data and the subsequent analysis. The fact that we based our interview probes on these models might explain that our analysis scheme proved applicable in analyzing patients’ responses. However, our probes were particularly directed to the cognitive processes that did not emerge in the answers as provided by the patient. Since patients frequently passed through the distinct cognitive processes spontaneously, further probing was often redundant. When we did use our interview probes, we phrased them open and non-directively. For example, a probe within the cognitive process judgment/combinatory algorithm was phrased as follows: “Can you explain how you did arrive at your response?”

In our attempt to reconcile deductive and inductive approaches, we chose to use the Three-Step Test Interview [8] that combines open, think-aloud with closed-probing techniques. This cognitive interview technique did stimulate us to stay open to new, unanticipated findings as well as to carry out a more structured exploration of relevant topics. Our results might be perceived as a product of these cognitive process models, since they also form the basis of our analysis scheme. However, to provide an open account of the cognitive processes used, we not only started the analysis with an initial reading of the interviews and summary of its salient content, but also actively searched for information that would not fit in or run counter to these models. We have developed our analysis scheme based on 80 responses of six cancer patients. In further using the analysis scheme on 342 responses of 50 cancer patients, no revision was required, which supports the comprehensiveness of our analysis scheme.
7.3. Examination of the assumptions underlying three designs used to measure change

7.3.1. Patients’ cognitive processes underlying QoL (change) assessment

The overall results regarding the assumptions inherent to the three designs can be summarized as follows. In the pretest-posttest design, the content of all cognitive processes changed over time ranging from 113 (out of 220; 51%) to 246 (out of 342; 72%) pretest-posttest comparisons. In the thentest design, changes in the content of the cognitive processes varied from 37 (out of 63; 59%) to 101 (out of 162; 62%) posttest-thentest comparisons. Additionally, in 102 out of 162 (63%) thentest responses, the time frame employed and/or descriptions of pretest functioning provided differed from those employed in the corresponding pretest items. In the transition design, patients did verbalize a comparison between current and prior functioning in 112 out of 164 (68%) responses to transition items. However, in 104 of these 112 (93%) responses, patients used a variety of other time frames instead of referring to their functioning at pretest and/or posttest according to the transition design’s assumption. Additionally, in 79 (71%) responses, the time frame employed and/or descriptions of pretest functioning provided differed from those verbalized when responding to the corresponding pretest items.

7.3.2. Reflections on the examination of the assumptions underlying three designs

The present study increased our insight into the way cancer patients arrive at QoL (change) assessments. Perhaps the most intriguing finding was that the content of the cognitive processes underlying QoL (change) assessments did not only differ among patients, but also within the same patient across items and over time. This finding holds for the pretest-posttest design, as well as for the thentest and transition designs. With this finding, we extend results from prior studies [9, 10] according to which changes in reference groups used at successive assessments of overall QoL appeared randomly. Additionally, it extends Rapkin & Schwartz’s theoretical QoL appraisal model [2], which was developed to describe the cognitive processes respondents use in answering an entire QoL questionnaire. Their assumption that respondents employ the same content of cognitive processes in answering all individual questionnaire items is refuted by our findings. We had concluded that the assumption(s) inherent to each design are not in line with the patients’ cognitive processes underlying over half of their responses. However, we can also state that in less than half of the responses, patients’ cognitive processes do support the assumption(s) underlying each design. Unfortunately, we lack a clear threshold against which we can evaluate the deviation in patients’ cognitive processes from the designs’ assumptions. In other words, the question arises whether our findings refute or support the designs’ assumptions. Although one would not expect to find a 100% support of the assumptions, how much agreement would be needed to claim such support? Based on the results from this qualitative examination, no design can claim ‘the victory’ in corresponding
most with the cognitive processes described by the patients. This study demonstrates that in all three designs patients provide QoL (change) assessments that are not necessarily based on the cognitive processes intended by researchers. Rather, patients were found to arrive at QoL (change) assessments based on content of cognitive processes that is personally meaningful to them.

Rapkin & Schwartz mapped change in the content of each of the cognitive processes constituting their QoL appraisal model to one of the specific types of response shift [2]: change in frame of reference is related to reconceptualization, change in sampling strategy and combinatory algorithm to reprioritization and change in standards of comparison to recalibration [11]. As demonstrated by Oort et al. [12, 13] all three types of response shift are 'a threat to the validity of within- and between persons comparisons if they remain undetected and unadjusted' [14]. This would mean that a change in the content of each of the distinct cognitive processes over time would contribute to invalidating QoL assessments. At an earlier stage, Golembiewski et al. [15] have distinguished three types of change that may occur in any pretest-posttest design consisting of self-reports. They defined these types of change as follows: ‘Alpha change involves a variation in the level of some existential state, given a constantly calibrated measuring instrument related to a constant conceptual domain (true change). Beta change involves a variation in the level of some existential state, complicated by the fact that some intervals of the measurement continuum associated with a constant conceptual domain have been recalibrated. Gamma change involves a redefinition or reconceptualization of some domain, a major change in the perspective or frame of reference within which phenomena are perceived and classified, in what is taken to be relevant in some slice of reality.’ (pp 134-135) [15]. Results from prior studies suggest a hierarchy between these three types of change, in which gamma change needs to be ruled out before beta change, and beta change needs to be ruled out before alpha change can be detected [16]. In terms of response shift, beta change matches recalibration response shift and gamma change is related to reconceptualization response shift. Following this line of reasoning, change in frame of reference leading to reconceptualization would be the most important underlying cognitive process. Thus, the question arises whether change in the content of one cognitive process is more important than change in the other, or that change in all these cognitive processes is equally important with respect to invalidating QoL change.

Several studies advocated the employment of cognitive methods such as think-aloud interview techniques to further elucidate how patients arrive at QoL (change) assessments [e.g. 2, 17-20]. For example, the use of such techniques was expected to improve the accuracy of self-reports [21] and responses to the then test [22], and to explain differences between the retrospective and prospective assessment of change [17]. Clearly, the current study did provide such explanations. At the same time, it also raises further questions about the way patients arrive at QoL (change) assessments. Importantly, we have examined patients' cognitive processes at the individual level. Numerous clinical studies have provided meaningful outcomes at the group level where the magnitude and direction of change were in the expected direction [e.g. 23, 24]. The extent to which our individual findings invalidate
QoL change outcomes at the group level is questionable. Rather, this study raises the critical question about how strict the assumptions underlying the three designs actually need to be adhered to in order to invalidate QoL outcomes at the group level.

7.4. It is not the patient who is ‘instable’

In receiving reviewers’ comments, it became painfully clear that labelling the content of cognitive processes over time as inconsistent was considered unnecessarily pejorative. To illustrate, we originally presented our results on dissimilarities in the content of the cognitive processes over time as ‘instability’ in the content of these cognitive processes. This resulted in an anonymous reviewer commenting "The human condition is one that we continue to grow from/with. (...) a debilitating disease and therapy does not make me "instable". It makes me human." Additionally, we labelled responses to transition items that were not in line with the assumptions underlying this design, as ‘not valid’. Our use of these words was perceived “offensive” by another anonymous reviewer, who stated “just because you can’t explain the patient-perceived rating does not make it any less real, valid or acceptable to use.” Naturally, it was never our intention to classify the patients as instable or invalid. These reviewers’ comments helped us to more carefully phrase our approach. Instead of asking whether patients’ cognitive processes meet the assumptions underlying the three designs, we have come to ask whether these assumptions are in line with patients’ cognitive processes. However, this subtly revised aim does not imply that patients’ responses to QoL items over time can be taken for granted. For example, in interpreting QoL change assessments we need to be aware that patients may use a variety of time frames besides those instructed in answering pretest, posttest, thentest, or transition items. Moreover, the content of each cognitive process underlying QoL assessment may change over time. It is important to note that perceiving the patients’ QoL assessments as inherently “true”, should not obscure the fact that patients provide QoL change assessments that are not necessarily based on the cognitive processes intended and interpreted by researchers.

7.5. Methodological reflections

The qualitative approach of this study yielded in-depth insight into the cognitive processes cancer patients used to arrive at QoL (change) assessments. However, the interpretation of data resulting from qualitative studies is inherently subjective. To enhance the intersubjectivity of our findings, analysis of all responses was independently carried out by two researchers, and all codes and subsequent analyses were discussed within the research team throughout the period of data collection and analysis. Additionally, the process of data analysis was made explicit and publicly available [6 (Chapter 3)]. Moreover we provided many examples of how the analysis scheme was used to code patients’ cognitive processes [6 (Chapter 3), 25 (Chapter 4), Chapters 5 and 6]. However, despite such efforts to ensure
the transparency and intersubjectivity of our analysis, other researchers might not have distilled the exact same findings. For example, in examining the assumptions underlying all three designs, we adopted a conservative approach to protect ourselves against a possible negative bias. We would like to illustrate this for the pretest-posttest design. When we had to decide whether the content of each cognitive process was similar at pretest and posttest, or rather changed over time, we concluded that the content was similar if no mutually agreed conclusion about (dis)similarity was reached. However, other researchers might have chosen to add a third category of 'doubt'. Additionally, the use of cognitive think aloud interviews might not adequately reflect the cognitive processes that respondents might use in arriving at QoL (change) assessments. Responses to questionnaire items are, in general, not the product of lengthy deliberations [26]. Several models distinguish between respondents who are 'satisfying' and 'optimizing' when answering survey questions. Optimizing respondents are motivated by accuracy and carefully pass through all distinct cognitive processes in arriving at a response. Conversely, satisfying respondents take a more unconscious route in providing a response [27, 28]. It is questionable whether these two approaches are actually distinguishable and mutually exclusive processes as purported in these models. For example, van Osch & Stiggelbout [29] demonstrated that respondents combine automatic and controlled strategies in arriving at a health assessment on a visual analog scale (VAS). However, in asking patients to think aloud while answering questions about their QoL, we might have 'forced' patients to primarily take the optimizing, or controlled, route in arriving at QoL (change) assessments. We cannot exclude the possibility that 'satisfying' respondents might have used different cognitive processes in the think aloud interviews.

7.6. Directions for future research

There is some evidence that the direction of change in QoL may affect the cognitive processes used to evaluate QoL. For example, according to Cella et al. [37] improvements and declines of comparable magnitude do not have the same meaning to the patient. They found that in comparison to improvement (i.e. positive change), the amount of negative change needed to be greater for cancer patients to be perceived as meaningful. To examine the influence of the direction of change on cognitive processes, we originally aimed to group participating patients into three categories, i.e. those whose symptoms or functioning improved, deteriorated or remained stable as a consequence of radiotherapy. This overall categorization would be based on external criterion measures of change based on the available clinical information at the time of the second assessment. However, during the analysis process we found that improvement, deterioration or stability did not differ per patient, but within patients per item. The radiation oncologists told us that there are no clear clinical criteria for the seven symptoms and functions we used. If they want to know how patients fare regarding these seven issues, they would just ask. Thus, a clinician-reported measure would actually be patient-based. To avoid such circularity in the criterion measures,
we decided to let go of the clinical categorization. However, in future research, it would be interesting to explore the possibility of categorizing patients according to clinical criteria, to further examine the possible influence of the direction of change in QoL on the content of patients’ cognitive processes. To that end, it would be interesting to replicate this study in a sample in which patients’ assessments of change in QoL can be associated with change in clinical indicators of health status. For example, for patients infected with human immunodeficiency virus (HIV)-1 such clinical indicators may include change in CD4-cell count, plasma viral load, body mass index and hemoglobin concentration [17]. Data derived from such a sample, might further reveal themes related to discrepancies between patients self-evaluation of change and clinical categorization of change. For example, do patients who report improvement in QoL, but who are clinically categorized as deteriorated, differ in the content of the cognitive processes underlying QoL assessment as compared to those whose self-evaluation concurs with clinical categorization?

This study focused on the content of the cognitive processes underlying cancer patients’ QoL (change) assessments. Our data demonstrate that patients might use processes to edit their initial response for self-protection, self-presentation and normalization. The content of the cognitive processes might be motivated by response strategies such as effort justification, social desirability, impression management and the reduction of cognitive dissonance. It would be interesting to examine the extent to which these psychological mechanisms motivate the content of the cognitive processes underlying QoL assessments. For example, one might design future studies in which patients at posttest are confronted with their prior QoL scores and verbalized cognitive processes, and are subsequently asked for their comments. Moreover, the respondents may be asked if they themselves consider the content of the cognitive processes used at pretest and posttest to have remained similar or to have changed. It would be interesting to examine possible discrepancies between researchers’ interpretations and respondents’ self-reports. This approach would provide valuable insight into patients’ own explanations of (dis)similarity in the content of the cognitive processes underlying their QoL (change) assessments, and would increase our understanding of the influence of various adaptive mechanisms on the content of the cognitive processes.

7.7. Implications for research

Our results show that each patient employed a variety of time frames besides those instructed in the QoL questionnaire, which indicates that the time frame perceived meaningful to the patient differs per QoL item. This finding does not only hold for retrospective assessments (i.e. thentest and transition items) but also for pretest and posttest assessments. However, this finding particularly refines previous recommendations to ensure a salient reference time for respondents who are asked to (retrospectively) assess their prior functioning [22, 30, 31]. Instead of using a single salient reference time for an entire QoL questionnaire (e.g. pre-treatment), one could also use different reference times per item.
(e.g. the onset of the symptom concerned). However, one should carefully weigh employing item-specific reference times against its disadvantages. For example, since the onset of symptoms might vary per patient, such an approach would imply a tailored approach. In addition, the use of different reference times per questionnaire item will increase the complexity of the recall task [32]. Responding to QoL questionnaire items is a complex cognitive task for respondents anyway [33, 34]. Adjustments to instructions accompanying a questionnaire and to the wording of items may facilitate this cognitive task [21, 35]. Study introductions that invoke specific content of cognitive processes may not only increase the accessibility of the requisite information [36], but may also enhance consistency in the cognitive processes and induce unambiguous interpretation. For example, patients might be explicitly instructed to employ a specific time frame in assessing their level of fatigue as a result of radiotherapy (comprehension/frame of reference) and to compare it with their level of fatigue prior to cancer diagnosis and treatment (standards of comparison). With respect to item wording, the target construct of each item should, wherever possible, be defined as concretely as possible to enhance a consistent interpretation of the item over time. These recommendations apply to all three designs. An adjustment specifically relevant for the transition design, is to explicitly instruct patients to compare posttest and pretest functioning to arrive at a change evaluation.

7.8. Implications for clinical practice

Our findings are of relevance for daily clinical practice. In line with QoL assessment in the pretest-posttest design, physicians ask their patients how they are ‘currently’ doing at consecutive visits. As this study shows, patients’ responses between visits might be incomparable. For example, a patient might base his/her assessment of functioning at one assessment using own functioning prior to cancer diagnosis and treatment as reference group, whereas he/she might use other cancer patients who are more severely ill as reference group at the following assessment. Clearly, such change in the cognitive process ‘standards of comparison’ will result in incompatible answers over time. The use of transition questions might correspond most with daily clinical practice, in which physicians ask their patients how they are doing since their last visit. Our findings imply that just asking a patient how he/she is doing since a prior visit, may elicit the answer “I am doing better”, which, however, cannot be taken for granted. Our results demonstrate that patients arrive at change evaluations based on personally meaningful experiences and complex cognitive processes. These cognitive processes might deviate from those assumed by the physician in interpreting the patient’s answer.

Naturally, the extent to which patients candidly answer physician’s questions will also be affected by other factors such as the perceived hierarchical nature of their relation with the physician, and the experienced stress during consultation [38, 39]. However, to increase insight into cancer patients’ health and wellbeing during the clinical consultation and
possible improvement or deterioration since the last visit, further probing regarding the content of the cognitive processes is recommended to increase insight into patients’ responses. For example in the assessment of pain, a physician might ask a patient to tell about his/her pain (i.e. comprehension/sampling strategy), on which specific experiences he/she bases the assessment of pain (i.e. retrieval/sampling strategy), and whether all these experiences are equally important in providing an assessment (i.e. judgment/combinatory algorithm). Furthermore, asking a patient whether he/she made a comparison to someone (standards of comparison) and assessed his/her level of pain ‘a little’ instead of ‘quite a bit’ (i.e. reporting and response selection) will increase insight into patient’s assessment of his/her current health status. With respect to change assessments (i.e. transition design), a question such as why the patient feels his/her pain has increased, decreased or remained stable will further enhance insight into patients’ self-reported ratings of change. Furthermore, it is our recommendation that physicians ask the patients to actively recall their last visit. Physicians can even help their patients to remember this last visit by summarizing their prior functioning as documented in their case histories. Subsequently, physicians can stimulate their patients to compare their current functioning with their remembered prior functioning and as a result arrive at a change assessment by explicitly asking them to pass through these steps.

7.9. Conclusion

To the best of our knowledge, this is the first study to qualitatively examine the assumptions underlying three designs commonly used in the context of treatment evaluation to measure change in QoL. Our data demonstrate that the assumptions inherent to these designs are not in line with the patients’ cognitive processes underlying the majority of their responses. Consequently, in interpreting QoL (change) assessments in the context of treatment evaluation, one needs to be aware of the fact that patients provide QoL assessments that are not necessarily based on the cognitive processes intended by researchers. Rather, we found that patients arrive at QoL (change) assessments which are meaningful to them, based on personal experiences and complex cognitive processes. Most importantly, the content of these cognitive processes not only differed between patients, but also within the same patient across items and over time. In building on cognitive process models and the response shift literature, this study contributes to a better understanding of patient-reported QoL assessment over time. As such, the present study has further opened the black box to shed light onto the cognitive processes underlying patients’ QoL (change) assessments.
References

13. Sprangers MAG, Schwartz CE. Do not throw out the baby with the bath water: build on current approaches to realize conceptual clarity. Response to Ubel, Peeters, and Smith. Quality of Life Research 2010; 19: 477-479


17. Nieuwkerk PT, Tollienaar MS, Oort FJ, Sprangers MAG. Are retrospective measures of change in quality of life more valid than prospective measures? Medical Care 2007; 45(3): 199-205


29. van Osch SMC, Stiggelbout AM. Understanding VAS valuations: Qualitative data on the cognitive process. Quality of Life Research 2005; 14: 2171-2175

201
31. Nieuwkerk PT, Sprangers MAG. Each measure of patient-reported change provides useful information and is susceptible to bias: the need to combine methods to assess their relative validity. Arthritis & Rheumatism 2009; 61(12): 1623-1625.