Understanding changes in quality of life in cancer patients: a cognitive interview approach
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Summary
In the introduction to this thesis, as presented in Chapter 1, the study’s background and general objectives are described. Patient-reported ratings of (change in) quality of life (QoL) are increasingly included in treatment evaluations to demonstrate treatment effects beyond clinical efficacy and safety. However, despite the abundance of data on QoL derived from such research, there is little knowledge on how patients actually arrive at QoL (change) assessments. Therefore, 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. More specific aims were to qualitatively examine the assumptions inherent to these designs.

Several studies have qualitatively examined one of the cognitive processes underlying QoL assessment in examining patients’ self-nominated QoL domains. To provide a comprehensive overview of the extant studies, we conducted a qualitative review on the domains somatically ill persons nominate as constituting their QoL. This structured literature review is provided in Chapter 2. Two types of studies were relevant for this review. First, studies using the Schedule for Evaluation of Individual Quality of Life (SEIQoL), which requires respondents to nominate five domains they consider most relevant to their QoL. When patients have difficulty nominating five domains, the SEIQoL prompt list, consisting of nine cues, can be used. Second, studies exploring patients self-nominated QoL domains to evaluate the content validity of existing, standardized QoL questionnaires. These studies use varying interview questions aimed at eliciting patients’ self-defined QoL domains, e.g. How would you describe your quality of life? Since the domains patients consider relevant to their QoL may be influenced by the method of enquiry, we compared the QoL domains presented in studies using the SEIQoL with those presented in studies using study-specific questions. We conducted two systematic literature searches in three databases, which yielded 36 eligible papers. The QoL domains presented in these papers were categorized according to the nine domains included in the SEIQoL prompt list and eight inductively generated additional domains. As was expected, SEIQoL studies reported the QoL domains used in the SEIQoL prompt list more frequently, whereas studies using study-specific questions more often reported the inductively generated QoL domains. Nonetheless, the influence of the method of enquiry on patients’ self-nominated QoL domains appeared limited: most QoL domains were presented by both types of studies, albeit with different frequencies. Importantly, cross-study comparisons were hindered by (a) limitations inherent to reviewing qualitative studies (e.g. the varying level of abstraction of patients’ self-defined QoL domains), (b) limitations of the included studies (e.g. insufficient information on the process of generating QoL domains), and (c) limitations inherent to our review process (e.g. other researchers might have proposed a different inductive categorization of the QoL domains). Therefore, we provided guidelines to address shortcomings of qualitative studies to enhance the transparency of the research process and subsequent report of qualitative
research aimed at exploring respondents’ self-nominated QoL domains. An initial step in increasing our understanding on how to interpret QoL (change) assessments was the development of a qualitative analysis scheme capturing the underlying cognitive processes. In Chapter 3 this endeavor is described. Based on a pilot study, we selected the questionnaire items, the interview procedure and interview probes. Subsequently, we conducted cognitive think-aloud interviews with six cancer patients prior to and at the end of radiotherapy to elicit the cognitive processes underlying the assessment of 7 items derived from the EORTC QLQ-C30. These interviews yielded 80 responses. These responses were first analyzed inductively and were then combined with deductive analysis based on the cognitive process models of Tourangeau et al. (2000) and Rapkin & Schwartz (2004). Combined, these models consist of five cognitive processes underlying QoL assessment: (1) induction of a frame of reference, (2) recall of relevant information, (3) use of standards of comparison against which the retrieved information is judged, (4) use of an algorithm to prioritize and combine the retrieved information, and (5) reporting and response selection. All distinct cognitive processes could be discerned in the patients’ responses. However, to fully capture the cognitive processes underlying QoL assessment, we extended the cognitive process ‘reporting and response selection’ with three editing processes: ‘self-protection’, ‘self-presentation’, and ‘normalization’. Our iterative analysis process resulted in a comprehensive analysis scheme. In addition, this study yielded a remarkable finding. In analyzing our data, we found that the content of the cognitive processes not only differed between patients, but also within the same patient across items. This resulted in the decision to analyze each response to all items separately in our main study. Change in QoL is most commonly assessed by means of the prospective pretest-posttest design. This design implicitly assumes consistency in the content of respondents’ cognitive processes underlying QoL assessment over time. In Chapter 4 the results of the examination of this consistency assumption are presented. In accordance with the design used in treatment evaluation, we administered pretest and posttest assessments prior to and at the end of a salient health-related intervention, in this case radiotherapy. To elicit the cognitive processes underlying QoL assessment, we conducted cognitive think-aloud interviews with 50 cancer patients undergoing radiotherapy. To ensure a heterogeneous sample and wide variation in cognitive processes used, patients were purposefully selected according to gender, age, tumor site and length of radiotherapeutic treatment. The interviews yielded 342 paired pretest and posttest responses, which were analyzed according to our previously established analysis scheme. To examine the consistency assumption, two researchers independently compared the content of each cognitive process between pretest and posttest, and determined whether the content was similar or rather changed over time. Dissimilarity in cognitive processes ranged from 113 (out of 220; 51%) to 246 (out of 342; 72%) pretest-posttest comparisons. The assumption underlying the pretest-posttest design was thus not in line with patients’ cognitive processes underlying at least half of their responses. The retrospective pretest-posttest or thentest design is the most commonly used approach to account for such inconsistencies, also labeled as recalibration response shift. The retrospective pretest or thentest extends the pretest-posttest design with a retrospective
evaluation of an earlier assessment. Most times, respondents complete the conventional posttest assessment, and are subsequently asked to complete the same questions again but with the instruction to report how they perceive themselves to have been prior to the pretest. The first assumption of this design is that by taking posttest and thentest in close proximity, the content of respondents’ underlying cognitive process will be consistent between posttest and thentest. Consequently, comparison of posttest and thentest scores would eliminate treatment induced response shift, and provide an unconfounded assessment of the treatment effect. The second assumption is that patients are able to accurately recall their pretest functioning when completing the thentest. Chapter 5 describes the examination of these two assumptions. We extended the pretest and posttest think-aloud interviews with thentest questions for 24 of the 50 cancer patients who completed the pretest and posttest interviews (Chapter 4). The thentest items were adapted versions of the selected seven EORTC QLQ-C30 items. Again, the patients were instructed to think out loud while providing a renewed judgment about their QoL at the time they conducted the pretest interview. The interviews yielded 162 responses per assessment. All responses were analyzed employing our analysis scheme. The assumption of consistency between posttest and thentest was examined similarly as in the pretest and posttest design, i.e. the content of each cognitive process was compared for all 162 paired posttest and thentest responses to examine whether it remained similar or had changed. Changes in the content of the cognitive processes varied from 37 (out of 63; 59%) to 101 (out of 162; 62%) posttest-thentest comparisons. Thentest design’s second assumption of accurate recall was operationalized by examining whether the time frame employed and the description of pretest functioning provided in answering each thentest item were similar to those of the corresponding pretest item. This was the case in only 60 out of the 162 (37%) thentest responses. In conclusion, the cognitive processes described by the patients in answering the majority of the thentest items appeared not to be in line with both assumptions underlying the thentest design.

In Chapter 6 the findings resulting from the examination of the assumptions underlying the transition design are presented. Transition items are administered after the posttest assessment and ask patients to rate the extent to which they have experienced change in their functioning since pretest. The assumptions inherent to this design are that patients (1) arrive at a change assessment by comparing posttest and pretest functioning, and (2) accurately recall their pretest functioning. In a subsample of 25 of the 50 cancer patients who completed the pretest and posttest think-aloud interviews, we administered the transition items and concurrent think-aloud interviews (Chapter 4). We transformed the selected seven EORTC QLQ-C30 items into transition items. Again, patients’ responses were analyzed according to our qualitative analysis scheme. Content analysis demonstrated that in 112 of the 164 (68%) responses to transition items, patients verbalized a comparison between current and prior functioning. However, in 104 (93%) of these responses, patients did not refer to their functioning at pretest and/or posttest according to the transition design’s first assumption, but rather used a variety of time frames as point of reference. Additionally, in 79 (71%) transition responses, the time frame employed and/or description of
prior functioning provided differed from those provided in the corresponding pretest items. Transition design’s assumptions therefore appeared not to be in line with patients’ cognitive processes used in the majority of their change assessments.

In the general discussion of this thesis, Chapter 7, the main findings of this study are addressed and discussed. Overall, our results show that the assumption(s) underlying each design are not in line with the patients’ cognitive processes underlying at least half of their responses. However, we lack a clear threshold against which we can evaluate this empirical deviation from the designs’ assumptions. Therefore, it is unclear whether our findings refute or rather support the assumption(s) inherent to the designs. Moreover, it should be noted that we have examined patients’ cognitive processes at the individual level. The extent to which our individual findings invalidate QoL change outcomes at the group level is questionable. 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. In this chapter, we also reflect on this study’s methodology. We discuss the a priori selection of the cognitive process models of Tourangeau et al. [1] and Rapkin & Schwartz [2] as this study’s framework, which can be considered both a solid theoretical underpinning and a limitation. Additionally, we address the use of cognitive think aloud interviews to reflect the patients’ cognitive processes, and our efforts to ensure the transparency and intersubjectivity of our interpretation of the data. Furthermore, we provide implications and directions for future research. For example, we suggest adjustments to instructions accompanying a questionnaire and to the wording of items. In future research, we suggest to examine whether the direction of change in QoL affects the cognitive processes used to evaluate QoL. Additionally, future studies might be designed, in which patients at posttest are confronted with their prior QoL scores and verbalized cognitive processes, and are subsequently asked for their comments. Finally, we provide implications for clinical practice. Most importantly, further probing is recommended to increase insight into patients’ assessment of their health.

In conclusion, 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, we found that patients arrive at QoL (change) assessments which are meaningful to them, based on personal experiences and cognitive processes. As such, the present study has further opened the black box to shed light onto the cognitive processes underlying patients’ QoL (change) assessments.