Summary
Quality of life (QoL) is considered to be an important goal in clinical practice and particularly relevant to palliative medicine. However, there is an awareness that the patients' own evaluations may differ considerably from those made by clinicians and significant others. Actually, QoL research often yields counter-intuitive findings. The expected deterioration in QoL often does not occur, even in the case of serious illness. It is suggested that the occurrence of response shift (i.e. a change in the meaning of one's self-evaluation as a result of a) a change in internal standards, b) a change in values or c) a reconceptualization) complicates the measurement of QoL, and may explain these discrepancies. Alternatively, response shift might be seen as a desirable outcome of adaptation. The aim of this thesis was to investigate: 1) the measurement of response shifts, 2) other phenomena to account for counter-intuitive findings in QoL measurement, and 3) adaptation from the perspective of the patient.

In this study the following research questions were addressed (Chapter 1):
1. Is the then-test a useful approach to determine whether a recalibration response shift has occurred?
2. Can response shift sufficiently explain counter-intuitive findings in the measurement of QoL?
3. Is SEIQoL-DW a reliable instrument in providing all the relevant information that is needed to determine whether a response shift (i.e. reconceptualization and change in values) has occurred?
4. What are the factors that result in positive self-reports despite deteriorating health.

We followed 31 patients with small-cell lung cancer during their illness trajectory. Patients who were evaluated for 1st line chemotherapy were informed about the study, invited to participate, and asked to give written consent. The patients were interviewed personally at home, they filled in written questionnaires (EORTC QLQ-C30 and QLQ-LC13) according to a ‘think aloud’ and a ‘then-test’ protocol, and individual QoL was assessed by means of the SEIQoL-DW. Our qualitative study included 4 measurements points during the first course of chemotherapy (i.e. T1 at the start of the chemotherapy; T2 4 weeks after T1; T3 at the end of the chemotherapy; and T4 6 weeks after the end of the chemotherapy), and 2 measurements during a second or third course (i.e. at the start and at the end of these courses, respectively).

**Listen to the patient**

Chapter 2 reports on the response behaviour in the measurement of fatigue with the EORTC QLQ-C30 question ‘were you tired’. For 15 out of 23 patients there were discrepancies between their answer to the EORTC question ‘were you tired’ and the level of fatigue they spontaneously reported during the interview. These patients chose the response options ‘not at all’ or ‘a little’, and explained their answers in various ways. Patients in the discrepancy group reported spontaneously how they dealt with the diagnosis and treatment. They distanced themselves from the image of the stereotype cancer patient presenting themselves as not suffering and accepting
fatigue as a consequence of the treatment. The results of our study show that the question ‘were you tired’ in the EORTC-QLQ-C30 does not unequivocally measure the impact of chemotherapy on the energy level of a patient. Patients seem to give the impression that they are managing the situation, and this self-presentation may explain unexpected results. In patients with and without discrepancies, we found indications of recalibration response shift (i.e. using a different standard of comparison over time) and change in perspective (i.e. change towards a more optimistic perspective). However, it was difficult to demonstrate recalibration by means of the then-test. The patients had difficulty in remembering either the previous measurement point and/or their fatigue at that time.

Chapter 3 describes the response behaviour in the measurement of physical and role functioning. The terminally ill patients evaluated their functioning in terms of what they perceived to be normal under the circumstances. Various response strategies when answering questions about problems and limitations in functioning explained why the patients had scores suggesting that QoL was affected very little by the chemotherapy. For example, the patients focused on one aspect of the question, took the wording of the question literally, ignored or excluded certain activities which they could not perform, and guessed their level of functioning in activities which they did not perform. These strategies gave the impression that the patients were less limited than they actually were. Their answers could be interpreted best in terms of response behaviour, which has been described by Rapkin & Schwartz, and the change in their appraisal of QoL explained how levels of physical and role functioning were sustained under deteriorating physical health.

**Focus on what matters**

Chapters 4 and 5 address the usefulness of the SEIQoL-DW (i.e. an individualized approach in the measurement of QoL in which patients can choose, value and weight five areas that they consider important for their quality of life) in the measurement of response shift. Chapter 4 reports on how patients choose and define the five areas, the so-called ‘cues’ and describes the problems that were encountered in the elicitation of cues. The instrument was found to be useful in eliciting what mattered to the patients. Many patients were eager to talk about sensitive issues. *Family* was the most frequently mentioned cue (i.e. patients named their partner, children, grandchildren and other family members) and some patients nominated more than one cue in this area. However, our study also demonstrated that eliciting cues implies that the interviewer makes decisions (e.g. about what to accept as a cue, whether and when to use the prompt list, and how to label and record the meaning of cues). SEIQoL-DW data are therefore vulnerable for unnoticed bias, because of intra- and inter-inconsistencies in the behaviour of the interviewer(s).

Chapter 5 describes the measurement of response shift with the SEIQoL-DW. Repeated measurements with the SEIQoL-DW generated data which showed that
the instrument had the potential to elicit important changes in priorities (i.e. the nomination of other cues), changes in perspective (i.e. change within a cue), and changes in values. Shifts in the perception of health, in particular, explained the high levels of functioning in this area and their contribution to good overall QoL. The audio-tapes of the interviews made it possible to assess these response shifts. There is a risk that repeated measurements do not provide all the information which is potentially available and relevant for the investigation of response shifts.

**Understand the struggle**

Chapter 6 describes adaptation through the eyes of the patient. The positive image which the patients presented was neither just the result of their own evaluation of health, nor just the result of successful adaptation and ‘practicing the art of living’. The patients actually knew their prognosis, but did not want to think about it, and tried therefore to anchor themselves to a positive attitude in order to survive emotionally. Especially through this sense of control the patients were able to let go, to revise goals and expectations, and thus to enjoy life, despite their deteriorating health. But, the art of living with a terminal illness sometimes required a daily need for willpower from the patients, and presumably also from their loved ones.

**Discussion**

Chapter 7 contains a general discussion of the findings presented in this thesis, and addresses implications for QoL and response shift research. Firstly, by listening to the patient who is filling in the questionnaire we discovered that not only response shifts, but also that self-presentation affects the QoL measurement. It will be a challenge for QoL and response shift researchers to investigate more in depth QoL appraisal, the phenomenon of self-presentation, and its place in the model of the response shift theory. Secondly, patients are eager to talk about sensitive issues in the SEIQoL-DW assessment, and the instrument is useful for investigating response shifts. We recommend that clear instructions are given to the interviewers, and accurate recording of the cues is essential to overcome the risk of interviewer bias. New research should be encouraged to investigate more in depth: 1) the use of the prompt list, and 2) the possibilities of using the instrument in clinical practice to identify patients who need help in adjusting to deteriorating health. Finally, our findings indicate that the positive self-reports in the measurement of QoL may cover up the efforts that patients have to make in order to survive physically, emotionally and socially, to keep going and still enjoy life. QoL and response shift research will benefit from investigating the struggle behind “I’m all right”, by observing QoL measurement in the real life context during the illness trajectory. Because each illness trajectory has its own characteristics, we recommend qualitative research in order to enhance the interpretation of QoL outcomes.