

Change in what matters to palliative patients: eliciting information about adaptation with SEIQoL-DW

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This study was carried out to investigate the usefulness of the SEIQoL-DW to elicit information about response shifts in palliative patients. The instrument measures individual quality of life and allows respondents to choose, rate and weight important areas of life (cues). We explored patients' reconceptualizations (ie, change in cues) and their value change (ie, change of cues weights). Results of 21 patients showed what mattered to these patients and how they had adjusted to deteriorating health. There is a risk that repeated measurements do not provide all the information that is potentially present and relevant to explore response shifts. But clear instructions to interviewers, such as careful listening, probing self-evident cues such as *health* and *family*, and accurate recording of cues on the forms may overcome this risk. Future research is recommended to explore the possibilities of regular assessments to facilitate better adjustment of patients. *Palliative Medicine* 2007; 21: 581–586

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Introduction

Quality of life (QoL) is considered an important goal in clinical practice and particularly relevant to palliative medicine.^{1–3} However, the expected deterioration in QoL does not occur often, even in cases of serious illness.^{4–6} There is ample evidence that the occurrence of response shift complicates 'objective' evaluation of treatment and quality of care.^{7–10} Alternatively, response shift might be seen as a desirable outcome of adaptation. From both perspectives, it is necessary to find out how response shift could be investigated.¹¹

Schwartz and Sprangers defined response shift as a change in the meaning of one's self-evaluation of a target construct as a result of (a) a change in internal standards of measurement, (b) a change in values or (c) a redefinition of the target construct (ie, reconceptualization). They evaluated different approaches to the measurement of response shift.¹¹ Two categories of approaches appeared to be immediately applicable, because they allow the use of existing QoL instruments: (1) design approaches, eg, 'then-test',¹² and (2) repeated use of individualized methods.³

The Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW)¹³ is an individualized approach that measures the unique individual perspective on QoL. Patients can choose, rate and weight five areas (cues) that they consider important. O'Boyle *et al.*³ defined change in cues between first and second interview as reconceptualization and change in the weighting of identical cues as value change. Two studies used the instrument explicitly to identify reconceptualization and value change. In the study of Echteld *et al.*,¹⁴ SEIQoL-DW was assessed in patients admitted to units for terminal care at one, three and five weeks after admission, in order to determine the extent to which response shift influenced QoL. Sharpe *et al.*¹⁵ investigated the relationship between response shift and adjustment in patients with metastatic cancer at baseline and at three and six months later. However, both studies differ considerably in the level of abstraction of nominated cues. Scharpe *et al.*, for example, reported *family* without further definition, whereas Echteld *et al.* reported *family* defined as 'maintaining good contacts with family'. In a previous study, we investigated the way in which patients choose and define their cues,¹⁶ and found that complete stories are told in the elicitation procedure and that the interviewer makes decisions what to write down on the form as label and definition. Therefore, we questioned whether the measurement of response shift could be prone to error when the meaning of cues (ie, patients' stories told in the elicitation) is not taken into account.

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It has been suggested that the SEIQoL-DW is useful for eliciting information about adaptation (ie, response shift). It has not previously been investigated that whether the data of repeated measurements are unambiguous and provide all the relevant information that is needed to determine whether response shift has occurred. We did so in a population of small-cell lung cancer (SCLC) patients during palliative chemotherapy.

Methods

Participants and procedure

Newly diagnosed SCLC patients, who were evaluated for first-line chemotherapy, were recruited from five outpatient clinics for chest diseases in the Netherlands. Participating patients gave written consent and were interviewed during the treatment trajectory. The project was approved by the Medical Ethics Committee of the VU University Medical Centre. The first interview (T1) was held at the start of chemotherapy, the second (T2) four weeks later, the third (T3) after completion of the chemotherapy course and the fourth (T4) six weeks later. The SEIQoL-DW was assessed, as described in the manual. Assessments were audiotaped and fully transcribed verbatim.

SEIQoL-DW

The SEIQoL-DW is administered in a standardized interview format.^{13,17,18} First, five areas of life (cues) that are considered central to the individual's QoL are elicited by asking: 'What are the five most important areas of your life at present . . . the things which makes your life a relatively happy or sad one at the moment . . . the things that you feel determine the quality of your life . . .?'. If cues are not nominated spontaneously, a list of nine frequently mentioned cues can be proposed.¹³ Secondly, the patients' perceived level of functioning within each cue is recorded, using vertical visual analogue scales ranging from 'as bad as could possibly be' (value 0) to 'as good as could possibly be' (value 100). Thirdly, the patients are invited to rate their current overall QoL on a horizontal VAS scale with the same anchors as the vertical scales. Finally, the relative importance (ie, weight) of each cue is recorded using a disk with five coloured sections, representing each elicited cue. Respondents are asked to change the sizes of the coloured sections by rotating labels attached to the sections until they correspond with the perceived weight of the cues. A total weight score of 100 is distributed over the five cues. An overall score (SEIQoL-index, range 0-100) is then calculated: the sum of cue levels multiplied by cue weights, and divided by 100.

Analysis of response shift

The findings reported in this article are based on two types of data: (1) the Cue Definitions Records Form (form) with

written information (ie, cues, definition, weights, Index-score and notes about procedure) and (2) transcripts of the audiotapes, which were analysed in Kwalitan 5.0, a software package for ordering qualitative data. Reconceptualization and value change was investigated in each patient (case) per transition, ie, determining changes in cues and their weighting between T1 and T2, between T2 and T3 and between T3 and T4. Reconceptualization was determined by comparing cue labels and their definition (patient's own words) as written on the forms. These findings were compared with information from the transcripts to determine whether the identification of cue change was correct. Analyses were performed by two members of the team (MW, TH). They categorized each instance of change and each instance of no change in cues per transition. They compared and critically discussed their findings in meetings, and a consensus was reached on the following categories:

1. Change in cues \Rightarrow supported by transcripts \Rightarrow reconceptualization
2. Change in cues \Rightarrow not supported by transcripts \Rightarrow false-positive reconceptualization
3. No change in cues \Rightarrow supported by transcripts \Rightarrow no reconceptualization
4. No change in cues \Rightarrow transcripts indicate reconceptualization \Rightarrow false-negative reconceptualization.

If no reconceptualization was found, a change in the weighting of identical cues was determined as value change if there was a minimum difference in weight of 10 points.

Results

Study sample

During the course of the study, 41 patients were reported to the interviewer and invited to participate. However, four patients were unwilling to participate and six were not interviewed because of imminent death. Of the 31 patients who were interviewed, six patients were excluded from the analysis because they were only interviewed once (they died within a month after T1) and four due to incomplete datasets (eg, confusion, distress, fatigue), resulting in a study population of 21. One patient was only interviewed twice at T1 and T3 and died before T4. Three patients were interviewed three times and died before T4, resulting in a total of 58 transitions in 79 interviews to explore for response shift. The mean age of the 21 participants was 58 years (range 39–72), 12 (57%) were female, 18 (86%) were married and 16 (76%) had children.

SEIQoL-DW during the treatment trajectory

The frequency of elicited cues ($n = 372$) and the mean SEIQoL Index and VAS are presented in Table 1. Cues related to *family* (eg, partner, children, grandchildren) were nominated

Table 1 SEIQoL index, VAS scores and frequency of important life areas (cues) elicited at T1 (start first-line chemotherapy), T2 (four weeks later), T3 (end chemotherapy) and T4 (six weeks later) in SCLC patients

QoL	Mean (range 1–100)			
	T1 (n = 21)	T2 (n = 21)	T3 (n = 20) ^a	T4 (n = 17) ^b
SEIQoL Index	70	83	77	82
SEIQoL VAS	70	75	81	78

Cue categories	Frequency (%)			
	T1	T2	T3	T4
Family	34	34	33	32
Health	16	17	16	23
Hobby/leisure	14	10	12	10
Enjoying life/holiday	7	8	11	13
Social life/other relations	7	10	11	9
Living conditions	6	6	3	2
Work	5	5	4	6
Autonomy/independence	5	5	5	1
Attitudes towards life	3	3	3	3
Finance	3	2	2	1

Note: ^a and ^b patients died before (n = 1) and after (n = 3) end of first-line chemotherapy.

most frequently. *Health* was the second most frequently mentioned cue (definition: eg, hoping chemotherapy would not be too tiring, being cured, successful chemotherapy, feeling well under the circumstances, hoping that the tumour would not reoccur). Other cues concerned *hobby/leisure* (definition: eg, fishing, gardening, making puppets), *social life/other relations* (definition: eg, visiting friends, distant family), *enjoying life/holiday*, *work*, *living conditions*, *autonomy/independence*, *attitudes towards life* and *finance*.

In 18 out of the 21 patients, a change in the nominated cues was observed, and mostly concerned a change of one to three cues. Some cues were important at one specific moment in time only. For example, *finance* nominated at T1 was not mentioned again at T2 because 'I'm no longer worrying about my husband's finances after my death'. There were two exceptions: (1) one patient changed all five cues at each interview; her cues were with very concrete wishes or goals, which differed at each assessment (eg, *wisdom to accept the situation*, *strengthening the relationship with my son*, *searching for new goals in life*) and (2) the other patient nominated only two cues in every interview and did not change these cues and their weights, ie, *relations* (level 100, weight 50) and *my independence* (level 100, weight 50).

In 16 out of the 79 interviews, the prompt list was used. At T1, 10 patients nominated two to three cues with the help of the list. At T2, five of them needed to be prompted again, but at T3, only one of these five still needed the list. At T4, the list was not needed anymore, but two patients, who had been prompted before, asked the interviewer to write down their previously nominated cues again because 'nothing has changed'. The time taken to complete the SEIQoL-DW ranged between 10 and 30 minutes.

A case study

The data as shown in Figure 1 are the illustrative information obtained from repeated measurements with SEIQoL-DW. Patient John (age 57) was not feeling well and suffered, among other things, for dyspnoea at the first interview (Figure 1a). Spontaneously, he nominated the cues *autonomy* (definition: I don't want to become dependent on others) and *family* (definition: my wife and children, I'm not important but they are). Three cues were prompted with the list, ie, *life circumstances*, *health*, *leisure* (definition: fishing with friends). The level of autonomy further illustrates his worries about dependency. His second interview was conducted after his last treatment cycle. He was feeling very well and eager to talk (Figure 1b). Without the help of the list, he nominated *family* (definition: my wife and children, I'm happy with their support), *health* (definition: feeling well) and three new cues *friendship*, *social contacts* and *work contacts*. The low level of work contacts illustrates his disappointment that his colleagues had not contacted him. Weights show *family* as the most, *health* as the second and *social contacts* as the least important. Five weeks later he died.

John's SEIQoL-DW data provide information about how he adapted during his treatment trajectory. However, further inspection of the transcripts showed more information, valuable in understanding how he had adapted. He had changed his definition of *family*. In his first interview, he had given a further definition of *family*, which was not written on the form, while he was rating the level of functioning: 'I'm worrying about whether everything has been arranged properly for my wife after my death, I have to arrange what's necessary'. This definition differed from the one at the second interview and written on the form 'my wife and children,

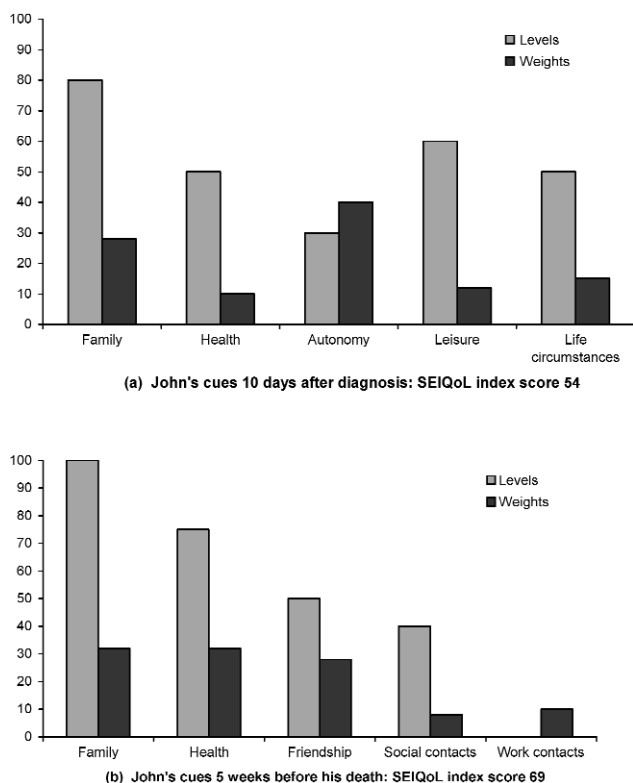


Figure 1 (a) Cues, levels of functioning and cue weights for a 57-year-old male patient with extensive SCLC, obtained 10 days after diagnosis at the start of first-line chemotherapy. *Family* and *health* were nominated spontaneously; *autonomy*, *leisure* and *life circumstances* were prompted with the list of most frequently mentioned areas. (b) Cues, levels of functioning and cue weights, obtained one week after the last treatment cycle of first-line chemotherapy and five weeks before death. Cues were nominated spontaneously.

I'm happy with their support'. Transcripts showed that the experience of feeling supported was new and special for him, and that he trusted his family with the necessary arrangements. Therefore, we concluded that a reconceptualization had occurred: the cue *family* had shifted from 'caring for his wife and children' to 'feeling supported by his family'. After further reading of the transcripts, the same phenomenon was seen with the cue *health*, which had shifted from 'getting cured' (transcript: 'that's what we fight for') to 'feeling well'. Both shifts in the meaning of cues were not detected by comparing the forms. Therefore, we categorized these instances of response shift as false-negative reconceptualization, because the SEIQoL had not detected these reconceptualizations. Furthermore, the transcripts showed a value change: 'I've changed my mind. I've said ... health was not important for me but, now I'm feeling well I've experienced how health strongly affects my life and, although not the most important thing, it is certainly the most decisive'. Because different cues were nominated and the definition of *health* had shifted, we concluded that nothing could be said about the magnitude of this value change.

Reconceptualization

We analysed 58 transitions in the way we did John's data (Figure 2). Reconceptualization was observed in 25 (43%) transitions and no reconceptualization in 16 transitions (28%). In 11 transitions (19%), no change in cues was seen but transcripts indicated that a reconceptualization had occurred (false-negative reconceptualization). These reconceptualizations concerned the cues *health* (seven times), *family* (two times), *leisure* (one time) and *work* (one time). In six transitions (10%), a conclusion about reconceptualization had to be withdrawn (false-positive reconceptualization, ie, change in cues not supported by transcripts), because differences in cues were a result of different wording, recording and/or response style (examples of false-positive reconceptualization are not reported, but are available from the first author).

Value change

In 12 patients (57%), a value change of more than 10 points was observed in at least one transition during treatment. Six patients weighted their *health* as more important at the end of the treatment with a mean change of 28 (range 10–64), and three patients weighted it as less important, with a mean change of 18 (range 12–27). *Family* was weighted as more important by two patients (change from 22 to 75 and from 20 to 33). One patient's weighting of *work* fluctuated during the treatment from 10 at the start of her chemotherapy (T1) to 3 four weeks later (T2). After the treatment (T3 and T4), she had plans to start with her work again and gave the area the weight of 16.

Discussion

Individual QoL appeared to improve remarkably within a four-week period from 70 to 83 at T2 and was higher than the

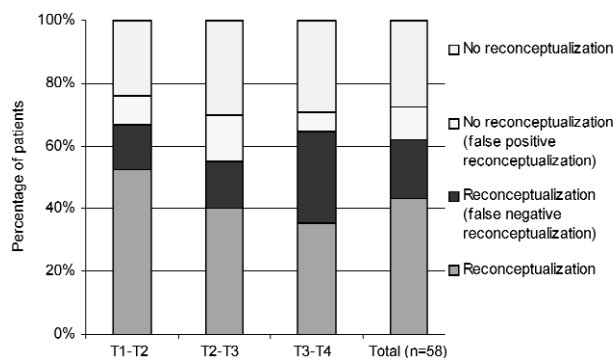


Figure 2 Measurement of reconceptualization with SEIQoL-DW in SCLC patients during first-line chemotherapy. Percentage of patients showing reconceptualization, reconceptualization not measured (false-negative), incorrectly measured reconceptualization (false-positive) and no reconceptualization.

SEIQoL-DW scores reported by Waldron *et al.*¹⁹ in advanced cancer patients and even in healthy elderly patients.⁵ After a slight decrease at T3, levels of T2 were reached again six weeks after the end of chemotherapy. Results of other studies in SCLC patients confirm this pattern.^{20,21}

Repeated measurements with the SEIQoL were generating data that showed immediately why 'expected deterioration in QoL doesn't occur'.⁴ Respondents changed their focus and emphasized more positive aspects, contributing to QoL instead of focusing on problems and concerns.²² The experienced support of the family and the knowledge that necessary issues such as finances had been arranged contributed positively to their QoL. These data showed how patients reconceptualized by nominating other cues that were important to them. The example of patient John showed that, solely by asking at two different points in time 'What are the five most important areas of your life at present ... the things which makes your life a relatively happy or sad one at the moment', it is possible to obtain information about a patient's adaptation.

Although not all reconceptualizations were detected by comparing the two forms, the instrument had the potential to elicit important changes in priorities (ie, the nomination of other cues), as well as changes in perspective (ie, change within a cue). 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 audiotapes of the interviews made it possible to assess these kind of reconceptualizations.

In six cases, the nomination of other cues was not a real response shift (ie, false-positive reconceptualization). This result confirms Westerman's *et al.* suggestions about dependency of the instrument on differences in the elicitation and recording of cues.¹⁶ Although standardization of cue elicitation (eg, standard use of list) could reduce this problem, it may increase the number of unmeasured (ie, false-negative) reconceptualizations, because it might prevent patients from talking freely about issues that are important to them^{14,23} and valuable information about adaptation could be lost.

Figure 2 shows a greater amount of false-negative reconceptualization at the T3–T4 transition, compared with T1–T2 and T2–T3. A possible explanation for this might be that at T4, all cues were spontaneously nominated, and because the patients were more experienced, the cues were nominated (and recorded on the form) more or less as a matter of routine.

Because SEIQoL generated relative cues that are constrained to unity,¹³ the measurement of value change has its shortcomings. Only when no change at all occurs in the nomination of cues, the value changes are clear. The nomination of just one new cue might also change the weight of the other four cues. In this study, we chose to investigate the prevalence and quality of value change and not to measure the quantity of change. However, reconceptualization and

value change are actually two interwoven concepts in SEIQoL-DW measurements. Although the nomination of a new cue could be considered as reconceptualization, it could also be considered as a value change or reprioritization (eg, nomination of *holiday* instead of *finance* suggests a value change of the cue *finance* to zero). The listing of cues in order of priority might overcome the earlier-mentioned problems in measuring value change (see eg, Sharpe *et al.*¹⁶) Furthermore, ranking opens up the possibility for the interviewer to ask at T2 for a ranking, including the cues that were mentioned at T1, but not mentioned at T2.

Conclusions and recommendations

The SEIQoL-DW was found to be useful in exploring response shifts. But, there is a risk that repeated measurements do not provide all the relevant information that is necessary to determine whether a response shift has occurred. Audiotaping was beneficial to us in detecting these pitfalls. However, it is not necessary to audiotape each assessment. It is recommended to listen carefully, to probe in particular the cues that are self-evident (*health* and *family*), to record the meaning of cues accurately and to give clear instructions when other interviewers are involved in the assessments.

In the assessment of SEIQoL-DW, valuable information was elicited about what really mattered to patients in the face of adversity and whether response shifts had occurred. Although several studies show that response shifts are associated with favourable QoL, the question that arises is whether response shifts might be induced in patients who have trouble in adjusting to changing health. Especially when a cure is unlikely, clinicians are just as concerned with changes in how a patient feels as with the more strictly physical aspects of the patient's medical condition. An important objective of therapy may be to facilitate changes in the way particular states are experienced. Wilson¹⁰ showed that, from a clinical perspective, response shift is not a new phenomenon and that facilitating coping processes in ways that improve QoL is part of clinical care. Therefore, our study justifies future research to investigate the possibilities of regular SEIQoL assessments in clinical practice to find out: (1) whether and how patients are able to adjust to changing health and (2) whether the obtained results can assist clinicians in helping patients to understand and to cope, and to rethink and reframe their experiences so that they can make the best of their condition.¹⁰

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