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ORIGINAL ARTICLE

Comparing two versions of the Schedule for Evaluation of Individual Quality of Life in patients with advanced cancer

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Abstract

Background. The aim was to compare two individualized patient reported outcomes or the Schedule for the Evaluation of Individual Quality of Life - Direct Weighting (SEIQoL-DW) measuring quality of life in general, and the disease-related version (SEIQoL-DR) measuring quality of life related to disease. Both instruments have been used in clinical practice settings within oncology. The instruments were compared with regard to feasibility, the areas nominated by patients as important and patients' ratings of how they were doing in these areas (Index scores). **Material and methods.** The study included 40 patients with gastrointestinal cancer. All patients completed both versions of the instrument on a touch screen computer in relation to a medical consultation. Firstly, the participants were invited to nominate the five domains she/he currently considered to be most important in life. Secondly, they were asked to rate how they were doing in each of these domains. Finally, they were asked to quantify the relative importance of each area. Cohen's effect sizes were calculated to illuminate the clinical importance of mean value differences. **Results.** Both instruments took less than ten minutes to complete and the procedure was considered feasible by both patients and interviewers. The proportion of patients nominating the same areas in the two versions did not differ, however, the SEIQoL-DW Index score was significantly higher than the corresponding score for the SEIQoL-DR. The detected difference in the mean score measured by effect size was medium. **Conclusion.** The magnitude of the effect size of the difference in Index score imply that the two versions tap into different constructs, i.e. quality of life (QoL) versus health-related QoL (HRQL), supporting the construct validity of the two versions of the instrument. The SEIQoL-DW and the SEIQoL-DR should be considered as complementary rather than interchangeable when used in patients with cancer.

In recent decades, there has been a dramatic increase in interest and development of quality of life (QoL) and health-related quality of life (HRQL) measures and a plethora of measures now exist for use in clinical research including clinical trials [1]. More recently these measures have also started to be incorporated into clinical oncology practice [2,3]. It is considered to be particularly important in trials comparing two different treatments when prognosis is poor and short-term gains in QoL/HRQL can be balanced against all negative effects [4]. Further, recent actions and statements regarding the value of HRQL in oncology populations have been further

substantiated by the U.S. Food and Drug Administration (FDA) Oncology Division's Meeting Recommendations for Avastin [5]. This highlights the FDA's expectation for improvements in symptoms or psychological state in tandem with progression-free survival or overall survival.

Studies examining QoL and HRQL have typically used standardized measures [6]. Such instruments usually include a predefined set of domains, often with a focus on health status, and have therefore been criticized for possibly missing domains important to the individual patient, while at the same time including other domains that might be of less

importance. Moreover, they assume that physical limitations, by default, must lead to decreased QoL [7,8]. This means that content validity with regard to standardized measures can be lacking, i.e., instruments might not capture what is most important to the actual patient population, or an individual patient. Individualized measures have been developed that allow respondents to choose the most important domains for themselves and these domains are the ones to be evaluated [9,10]. Hence, this approach is proposed as a more suitable approach than standardized measures in capturing patients' perspectives. Furthermore, monitoring individual patients' QoL has been proposed as a useful tool for care planning and follow-up of individuals in clinical practice [11].

One of the most widely employed individualized measures is the Schedule for the Evaluation of Individualized Quality of Life - Direct Weighting (SEIQoL-DW) [12], which is a generic QoL instrument purporting to capture the impact of areas in life considered to be most important for the respondents overall QoL. The SEIQoL-DW is based on an idiographic approach, which aims at assessing QoL as defined by the individual patient. A recent review found SEIQoL-DW to be feasible and valid, however the findings regarding capturing changes over time (responsiveness) were inconclusive [13]. SEIQoL-DW has been used in a range of cancer patient populations [14–16], including gastrointestinal (GI) cancer patients [17]. GI-cancer patients in advanced stages have a poor prognosis with median survivals often less than half a year, while anti-tumor treatments, typically different cytotoxic drugs, prolong median survival with a few months [18]. If given in several lines, the total median survival gain may reach 12–36 months in colorectal cancer [18]. Studies have shown that this patient group considers it important to discuss more psychosocial aspects like QoL areas with their physician in a clinical practice setting, and that the use of SEIQoL-DW is a feasible way to promote this type of communication [17,19].

Hence, the aim of this study was to compare a more recent disease-related SEIQoL version [16], the SEIQoL-DR, with the generic SEIQoL-DW, i.e. the original version of SEIQoL-DW. The disease-related version captures the domains that the patient perceives most affected by disease and treatment at an individual level [16]. Initial results show that the two SEIQoL versions tap into different constructs [20]. More specifically, the aim of this study was to compare the generic SEIQoL-DW with the disease-related version, regarding feasibility, nomination of areas of importance and Index scores in GI cancer patients.

Material and methods

Patients

A purposive sample of consecutive out-patients with GI cancer, at Akademiska Hospital (Uppsala) and Karolinska University Hospital (Stockholm), were invited to participate in the study from April through August 2004. Patients were 18 years or older, spoke and understood Swedish well enough to take part in an interview and had not been enrolled in another QoL study lately. Heterogeneity was sought regarding the patients' disease stage, treatment, age, and gender. In total, 40 patients consented to participate.

Instruments

The SEIQoL-DW has most commonly been administered using semi-structured interviews. Lately a computer administrated SEIQoL-DW has proved to be a valid alternative to the original mode of administration [14]. Firstly, participants are invited to nominate the five domains s/he currently considers to be most important in life [12]. Secondly, they are asked to rate how they are doing in each of these domains. Finally, they are asked to quantify the relative importance of each area, by adjusting the sizes of five differently colored areas in a pie chart representing the identified life areas. All areas add up to 100 and the area perceived to be of greatest importance should be assigned the largest pie area. An overall QoL index score to enable comparisons at group level is calculated by multiplying the rating of each area with the same domain's weight and summing the products.

The disease-related version uses the same procedure for nomination and weighting of life areas, and an Index score is calculated [16]. The versions differ in that the DR version asks the respondent to nominate the areas in life *influenced by the studied disease and treatment* for the target patient population, i.e., in this study GI cancer and its treatment.

Procedure

All patients completed both versions of the instrument on a touch screen computer in relation to a medical consultation, with an interviewer present to assist if needed. All patients completed the SEIQoL-DW first followed by the DR-version. They were asked to think aloud when filling out the tests. The patient received two copies of the results, one to keep and one to give to the doctor. The perceptions of doctors and patients regarding the use of QoL results in clinical practice have been published previously [17].

The study was approved by the regional ethics committee, Uppsala University.

Analyses of interviews

Feasibility was evaluated based on time for completion of the instruments, as well interviewer's and patient's perceptions of their usability. The interviewer recorded ease of completion, if the procedure was understood and completed, and the respondent's interest in completing the measure. The respondents' were also asked if they found the results to be in agreement with how they perceived their own QoL.

Statistical analyses

Chi-square statistics were performed to determine potential differences between the versions in categorical variables (interviewer's evaluation, patient's perceptions, nominated cues). Dependent t-tests were calculated to determine differences in the Index scores. P-values < 0.05 were considered statistically significant. To evaluate clinical significance Cohen's effect sizes were calculated for the difference in the Index scores and the mean completion time for the two versions. According to Cohen's classification standards, $d = 0.20$ – 0.50 indicates a small difference, $d = 0.51$ – 0.80 a medium difference whereas $d > 0.80$ indicates a large difference [21].

Results

Forty patients with GI cancer participated in the study (mean age 58.4 years; range 33–78 years; 50% women). The clinical characteristics and the treatments at the time of the interview are shown in Table I. All patients filled out both versions of the instrument on a touch screen computer; there was no missing data.

Feasibility

The time for completion was significantly shorter for the SEIQoL-DW (Mean 6.2 minutes, SD 2.7) than for the SEIQoL-DR (Mean 7.5 minutes, SD 4.3;

$p < 0.05$; Effect size 0.36). However, both versions took less than 10 minutes to complete.

A majority of the patients had no difficulty to nominate five areas regardless of used version (DW: 80%; DR: 74%), they considered the procedure easy to complete (DW: 85%; DR: 83%), and had an interest in completing the measures (DW: 73%; DW: 70%). Most patients considered the measures to be 'feasible' or 'quite feasible' to fill out, while 12% considered it to be 'initially difficult' and 10% found it to be 'difficult'. A majority (95%) of the patients considered the results to be in 'total agreement' or 'fairly in agreement' with how they perceived their own QoL. The two versions did not differ significantly regarding ease of nominating areas, procedure for measurement or interest in completing the measure.

Areas of importance

The areas nominated as most important in life were the same for both versions, i.e., family, health, leisure, finances and social activities (Table II). The proportion of patients nominating a specific cue did not significantly differ between the two versions. Further, the areas did not differ with regard to the nominated areas *per se* but rather to *how* the areas are evaluated by the respondents. For example, a patient may rate family relations higher in the generic version than in the DR version. From the perspective of having cancer negative consequences may be included, i.e., feelings of guilt, difficulties getting around and doing things, aspects not included when viewing family relations from an overall level (generic version).

SEIQoL-DW Index score and SEIQoL-DR Index score

The index score for the generic version (78.9; SD 16.8) version as compared to the DR-version (68.4; SD 19.5) was statistically significant higher ($p < 0.001$, Effect size 0.58).

Table I. Characteristics and treatments of interviewed patients with gastrointestinal cancer, number of patients presented.

Diagnosis	Clinical situation ¹	Ongoing treatment			Total N = 40
		Chemotherapy	Radio (chemo)-therapy	Supportivecare only	
Gastric cancer	Palliative	1		1	2
Pancreatic cancer	Palliative	3			3
Hepato-biliary cancer	Palliative	2			2
Colorectal cancer	Curative	8			8
	Palliative	16	1	4	21
Anal cancer	Curative		3		3
	Palliative		1		1

¹Curative means that either pre- or postoperative treatment, or in anal cancer radical radiochemotherapy, was given, aiming at cure. Palliative treatment generally in metastatic disease means that it was given with the purpose of influencing tumor-related symptoms, improving QoL or prolonging survival.

Table II. Nominated cues for the SEIQoL-DW and the SEIQoL-DR, respectively.

Cue	SEIQoL-DW N = 200*	SEIQoL-DR N = 200*
Relationship	56	43
Health	39	45
Leisure	37	29
Finances	24	32
Social activities	23	26
Physical activity	11	13
Independence	4	4
Living conditions	3	1
Mental strength	1	4
Religiosity	1	1
Health care	1	1
Total	200	200

*Each patient nominated five cues summing up to 200 cues/instrument.

All cues are aggregated cues.

Discussion

This study compared the usability and construct validity of the original, generic SEIQoL-DW and the disease-related SEIQoL-DR in GI cancer patients. Both instruments appeared to be feasible and the range of nominated areas did not differ between the versions. However, patient's evaluation of the areas (ratings) differed by version and the two versions should be considered as complementary rather than interchangeable instruments when used in cancer patients. These results are useful for clinicians who want to use a QoL or a HRQL instrument in clinical practice to monitor their patients and potentially also for giving input to the patient-physician communication.

The disease-related Index score was significantly lower than the Index based on the original DW-version. The effect size is calculated to be able to evaluate the clinical importance of a statistically significant difference which in this case was found to be of medium magnitude which means that the difference in scores between the two versions can be considered clinically significant. This indicates that the two measures partly tap into different constructs, or, QoL versus HRQL. It appears possible for most patients to appreciate life and have a good QoL from a general point of view, despite being bothered by disease and its treatments. Actually, in the far majority of the patients, the ratings of generic domains were higher than the ratings of disease-related domains. This circumstance has been reported previously in patients with serious disease, such as cancer and amyotrophic lateral sclerosis [15,22,23]. The results underscore the importance to distinguish between QoL and HRQL, as these concepts are not interchangeable [24]. Overall QoL reflected in the generic SEIQoL-DW Index score may be a useful

indicator of how well patients have adapted to their present situation and get along, whereas the DR-Index score is the most useful for comparing different interventions in a clinical study or for identification and monitoring of needed health care interventions.

A previous study which elucidated the content of areas through analysis of the interviews, using a think aloud approach, found that statements describing the areas of the disease-related version were more problem-oriented despite labeled with the same heading as the original version [20]. How patients reasoning differ when nominating areas important for overall QoL versus HRQL will be further explored elsewhere when analysis of patients' interviews will be presented.

Despite significant difference in time for completion, both versions took less than ten minutes to complete and the touch-screen procedure was considered easy to understand and use. The net time for completion may be even shorter, since the think aloud approach most likely added extra time to the procedure and further with repeated administration patients will be familiar with the procedure. The DR version was completed last, which could have meant a "learning" effect with regard to the procedure [14]. Still, this effect might have been counterbalanced by the DR-version opening up for thoughts related to having cancer, which meant patients had to switch to a new framing which may be cognitively demanding. The procedure for both instruments was perceived as feasible by a majority of the patients. Furthermore, over 90% of the patients thought that the results reflected their own perception of QoL. The feasibility and psychometric properties like responsiveness of the instruments is recommended to be further investigated in different settings in cancer care such as in addition to clinical consultations and by nurses to assess needs of health care in hospitalized patients.

In conclusion, the generic and disease-related SEIQoL, administered by touch screen computer, are feasible measures among patients with GI cancer in different stages. The two versions appear to tap into partly different aspects and they may therefore be considered to be complementary to each other rather than interchangeable. These instruments may help to distinguish between the level of patients' overall QoL, i.e., arrange of physical, social and emotional factors in life that may counterbalance the negative influence of the disease, and their HRQL, i.e., factors most affected by disease and treatment. While the generic version allows for capturing a holistic perspective of QoL in accounting for constructive coping mechanisms, the DR version targets problems that may be within reach for medical

interventions. These results are useful for clinicians who want to use a QoL or a HRQL instrument in clinical practice to monitor their patients and potentially also for giving input to the patient-physician communication and shared decision making.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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