

Patients' and Doctors' Views of Using the Schedule for Individual Quality of Life in Clinical Practice

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Quality-of-life (QOL) assessments mostly have evaluated the efficacy of competing medical or psychosocial interventions.¹ However, QOL instruments may be useful in formulating care planning and tracking follow-up of individuals in clinical practice.^{2,3}

Eliciting cancer patients' concerns and addressing them early are important in avoiding psychiatric morbidity.⁴ Patients' major concerns often are related to psychosocial issues. Patients and doctors readily discuss physical aspects of illness and its treatment, but they also want to discuss QOL issues during the consultation⁵; however, each group expects the other to initiate discussions on psychosocial issues.^{4,5} Thus, doctors' informal screenings of patient concerns leave many problems unrecognized and, therefore, untreated.^{4,6}

Patient-reported outcome measures are a promising strategy to enhance patient participation during the consultation.⁷ Implementation of a QOL instrument may improve the standard clinical interview and allow more systematic confrontation of psychosocial concerns.⁸ Results of randomized, controlled studies confirm that repeated feedback to doctors of QOL results from the cancer-specific European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire-Core 30 (EORTC QLQ-C30) has led to greater attention to QOL issues.^{9,10} The only study detecting effects on QOL achieved this by both completion of the instrument itself and feedback of results to the doc-

Abstract This study explored patients' and oncologists' perceptions of using a computer-administered, individualized quality-of-life (QOL) instrument to support an oncologic consultation. Twenty patients with gastrointestinal cancer (50% female; mean age 60 years) at two hospitals in Sweden completed the Schedule for the Evaluation of Individual Quality of Life-Direct Weight (SEIQoL-DW) and the Disease-Related (DR) SEIQoL-DW and brought the results to the consultation. Afterwards, interviews were conducted with all patients and six of eight doctors. All interviews were audiotaped, transcribed, and analyzed using an interpretivist approach. Most patients and doctors believed that the instrument would facilitate detection of patients' areas of concern and would support monitoring of patients' QOL. This tool may empower the patient, give the doctor a broader picture of the patient, and influence clinical decision-making. The SEIQoL-DW may be a systematic method of stimulating patient-centered care. It apparently encourages patients to reflect upon their own situation and allows them to be seen as whole persons. However, further quantitative evaluation of the intervention's outcomes is required.

tor.¹¹ However, a positive effect on emotional well-being was achieved only when doctors received the EORTC QLQ-C30 results.

Gaining an Individualized Perspective

Most QOL instruments used so far, including the EORTC QLQ-C30, have been standardized. To gain access to individual patients' views, the use of instruments that adopt an individualistic approach may be more appropriate.^{2,12}

QOL has been defined as the gap between the individual's expectations and achievements.¹³ This suggests that individual patients ideally should identify and prioritize components that are important to them and assess the impact of disease on each of these components.¹³ The Schedule for the Evaluation of Individual Quality of Life (SEIQoL)¹⁴ is an example of a measure that takes the individual into account.

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Individualized instruments, which incorporate topics of most concern to individual patients and capture their ratings and weightings, have appeal for use in clinical practice.¹⁵ These measures may stimulate a dynamic interaction between patient and provider based on knowledge about individuals' personal values and priorities.⁷ In addition, these instruments may empower patients and improve communication during the consultation¹⁶; however, there is no empiric evidence of these effects.⁷

According to Greenhalgh and colleagues,¹² to date, studies of patient-reported outcomes in clinical practice "have focused almost exclusively on determining *whether* the intervention works, without adequate consideration of *how the* intervention might give rise to expected outcomes," such as the mechanisms through which outcomes are achieved. The presumed impact on clinical decision-making rests on several assumptions (eg, that the QOL instrument reflects the patients' views, that clinicians and patients are willing and able to use the instrument, and that the physicians act upon detected problems). Qualitative research approaches may help to clarify complex healthcare interventions and their potential effects; they have been presented as a means of optimizing interventions before formal randomized controlled studies are performed.¹⁷ Allowing parties who deliver and receive the intervention to express views in their own words may provide information that would otherwise remain undetected if standardized questionnaires with predefined questions and answer categories were used.

Overall, this study explored patients' and oncologists' perceptions of individualized QOL assessments—the SEIQoL-Direct Weight (SEIQoL-DW) and the Disease-Related (DR) SEIQoL-DW—to support the consultation.

Completion Procedure for the SEIQoL-DW and the DR-SEIQoL-DW

In the first step of the Schedule for the Evaluation of Individual Quality of Life-Direct Weight (SEIQoL-DW), patients were asked to identify the five areas (or cues) of greatest importance to their current overall quality of life (QOL). If patients had difficulties in identifying five areas, they could use a prompt list of areas (eg, family, health, and work) that were nominated by patients in earlier studies.¹⁶ Next, the patients were asked to determine their current satisfaction with each area on a visual analogue scale from 0–100 (worst possible to best possible). Finally, patients were asked to quantify the relative contribution of each area by adjusting the sizes of their life areas, represented by five differently colored areas in a pie chart on the screen. All areas had to add up to 100; patients assigned the highest number to the area they perceived to have greatest importance. The Disease-Related (DR) SEIQoL-DW was completed in the same manner; however, areas nominated were the five areas (cues) of greatest importance to the patient's disease-related QOL (ie, life areas that patients believed were most affected by their disease and its treatment).¹⁸

Methods

PARTICIPANTS AND SETTING

A purposive sample of patients diagnosed with gastrointestinal (GI) cancer who were being treated at the Akademiska Hospital (Uppsala) and at Radiumhemmet, the Karolinska University Hospital (Stockholm), were invited to take part in the study between April 2004 and August 2004. Participants had to be 18 years or older, speak and understand Swedish, be well enough to take part in an interview, give consent, and not have been enrolled in another QOL study. Heterogeneity was sought regarding the patients' disease stage, treatment, age, and gender. Patients received a written invitation and information; they later received a phone call from the interviewer, who asked whether the patient was willing to participate. All 8 oncologists who treated at least one of the participating patients at either of the two hospitals were invited to take part in an interview. The study was approved by the Regional Ethics Committee for Human Research at Uppsala University.

INTERVENTION

All patients completed the original SEIQoL-DW and the DR-SEIQoL-DW on a touch-screen computer immediately before their medical consultation; an interviewer was present to assist, if needed (see Box).^{16,18} The computer-administered version of the SEIQoL-DW is a valid alternative to the original mode of administration.¹⁹

After completing the questionnaires, the patient immediately received two copies of the results—one to keep, and one to give to the doctor. The presentation format of the results appears in Figure 1.¹⁸ Results from the SEIQoL-DW provided information on the patients' overall QOL,¹⁴ whereas those from the DR-SEIQoL-DW provided information on life areas affected by the disease and/or its treatment.¹⁸ When the DR-SEIQoL-DW was transferred to the touch-screen format, a 7-point Likert scale was replaced by a visual-analogue scale ranging from 0–100, as used in the SEIQoL-DW.

Before the study, all doctors viewed demonstrations of the touch-screen versions of the SEIQoL-DW and the DR-SEIQoL-DW and examples of how the QOL results could be used during the consultation.

INTERVIEWS

Qualitative, semistructured interviews were conducted with patients immediately after each consultation to identify their perceptions of the QOL instruments. The interview guide included questions about if, and how, the QOL results were used during the consultation and about potential pros and cons of using the SEIQoL-DW in routine care. Investigators considered saturation to be achieved when additional interviews introduced no new information; further patient recruitment then was stopped. Participating doctors were interviewed at the end of the study to explore their views of

the instruments. Interviews lasted 10–20 minutes; they were audiotaped and transcribed verbatim.

ANALYSES

An interpretivist approach was used to determine variations in respondents' perceptions of individualized QOL instruments in clinical practice. Analyses were carried out independently by two of the authors using the software program NVivo.²⁰ Transcripts of the patients' and doctors' accounts were read, and perceptions relating to the aim were identified and coded with headings describing their content. These emergent headings were redefined iteratively and organized hierarchically into a system of categories and subcategories. Differences in the independent analyses were resolved via discussions, and a consensus version of the results was established.

Results

PRESENTATION OF RESULTS

Main categories are presented in the beginning of each section. Subcategories are highlighted in the text by use of italics. The quotations in the results section were selected based upon how well they illustrate the content of the category under consideration. Parts of the quotations without importance to the category in question have been left out (ie, marked as "...").

BACKGROUND CHARACTERISTICS

Of 22 patients who agreed to participate, 20 were interviewed; 1 patient was unable to complete the instrument, and another did not have time to stay for the interview because of a delayed physician visit. The final patient sample contained equal numbers of women (n = 10; mean age, 59 years; range, 33–73 years) and men (n = 10; mean age, 62 years; range, 49–78 years). Different socioeconomic groups were represented. Thirteen patients had colorectal cancer, 5 had pancreatic cancer, 1 had biliary tract cancer, and 1 had gastric cancer. Stages of disease and treatments given differed. Six (two female, four male) of eight oncologists working in the departments of GI cancer were able to participate in the interview process.

PATIENT VIEWS OF INDIVIDUALIZED QOL DATA

The patient interview data generated two main categories—use of the individualized QOL results during the consultation and views of the use of individualized QOL assessments in clinical practice. The first category refers to the patients' own experience of bringing QOL results to the consultation. The second category embraces the patients' general perceptions of QOL assessments in clinical practice after they received some insight.

Use of the individualized QOL results during the consultation: During some consultations, the QOL results spurred a discussion about the patients' prioritized areas and their QOL in relation to care and treatment. Sometimes, such discussion resulted in the detection of problems and action by the physician:

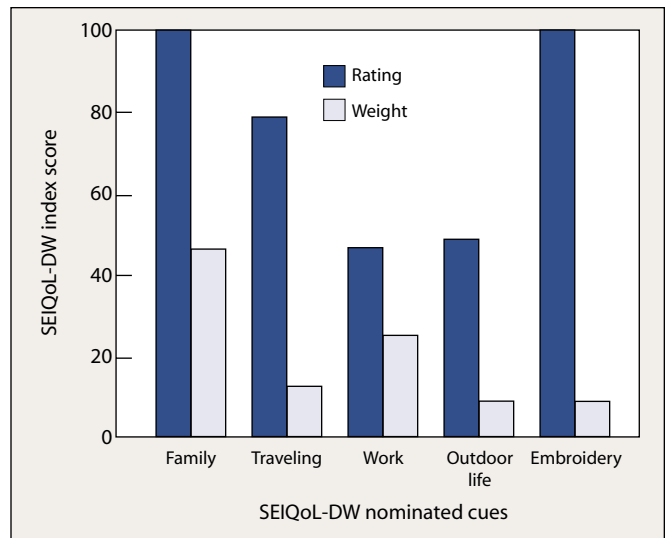


Figure 1 QOL Profile of a Female Patient With Gastrointestinal Cancer

Scores are measured between 0 (worst possible QOL) to 100 (best possible QOL). Index score (Σ levels \times weights) = 79.5.

Abbreviations: SEIQoL-DW = Schedule for Individual Quality of Life-Direct Weight; QOL = quality of life

Patient 9: Yes, we talked a little about it [the QOL results]. It was about sexual activity and things. But then I said that it's not that much of that nowadays, because it hurts /.../ I thought that I should wait and see until it gets better and that it's the treatment causing this. But no, no, it should be taken care of now, [the doctor] said, and wrote a referral to a gynecologist /.../ And I brought it up, he might not have done that, because these matters are a bit sensitive /.../ but you don't try [to have sex] if it hurts, do you?

In another case in which the results revealed a similar problem, it seemed that both the patient and the doctor avoided further discussion, and no action was taken:

Patient 17: Yes, he had a look [at the QOL results]. We got some time at the end [of the consultation]. He glanced through them. He didn't say that much.

Interviewer: /.../ You didn't, for example, discuss your poorly functioning sexual life [referring to the results]?

Patient 17: No, we both had shifty eyes faced with that. No, I don't know, this is the first time that I have mentioned this to anyone, except to my husband.

However, several patients reported that their QOL results were not used during the consultation, even though the results were handed over to the doctor. Although some patients believed that this omission was due to time pressure and prioritization of other aspects of the disease or treatment, others believed that the doctor either was not interested in the results or was unsure of how to use them. Some patients believed that the doctor would review the results after the consultation.

Patients' views of individual QOL assessments in clinical practice: Nearly all patients were optimistic about the routine use of the instrument in clinical practice and believed that it

would facilitate follow-up of their QOL. Some patients referred to the instrument as a “checklist” that ensures that problems are detected and resolved (eg, by referral to supportive counseling). The instrument’s focus on patient-defined concerns was appreciated, since patients and doctors may differ in their perceptions of the most important problems:

Patient 17: I think that it's difficult to talk to a doctor. What's essential and what's not? What should you say when you meet a doctor? /.../ For example, if I have an itch, that might be my biggest problem, even though it's a small problem in the eyes of the doctor. Like, 'Yes, she's still yellow under her eyes.' That's much more interesting [to the doctor].

Several patients acknowledged that the instrument *encourages the patient to reflect* upon his/her own overall life situation. “It forces one to think” (Patient 21) and to “sort the important from the less important” (Patient 6) in the light of the disease. Patients may be *empowered* by the use of the instrument, since it makes it easier for the patients to *voice their concerns*:

Patient 3: I think it's good in the way that if you have something like this [QOL results], then you can actually tell the doctor that, 'Now I would like to talk about this and that,' and then he'll have to listen /.../ It gives the patient a better position, and maybe that's [the advantage]. Not the questions themselves, but rather that the doctor has to [listen].

Some patients believed that the instrument would give the doctor a broader picture of them, and that it underscored the importance of the individual—not just being considered a number but being confirmed as a whole person:

Patient 2: The advantage might be that if the doctor looks at this, and you talk about it, then it might fill out the doctor's view of me. How I react on things and how I feel now, if I feel well or bad and why, and so on. It can be useful to the doctor in relation to future treatment, in the judgment of things.

The patients also believed that the *usefulness* of the instrument would *differ among patients*; it may be more important to those who are terminally ill, suffer from considerable emotional distress, or lack a social network.

Patient 22: The worse the stage [the disease] gets, the more it has developed, the more important [the QOL assessment] gets. Now, when I meet the doctor, we talk a lot about technical matters, how to proceed, which treatments you should get, and so on. I'm not that far gone. If it turns out that [the disease] gets worse and worse, of course, [the QOL assessment] gets more important.

Few patients could identify any potential disadvantages of using these instruments in clinical practice. However, some believed that QOL assessments are *outside the doctor's area of responsibility* or *covered in the consultation anyway*. Others thought that implementation of the instrument might be difficult due to *time constraints* and because, according to Patient 14, “some doctors may not take surveys like this that seriously, and, in that case, it has not fulfilled its purpose.”

One respondent believed that using the instrument might *cause anxiety* in patients by triggering existential thoughts. None of the interviewees, however, expressed any anxiety for their own part, although one patient feared that potential

spreading of the QOL results to the social insurance office could jeopardize the sickness benefit if they revealed that the patient could work.

PHYSICIANS' VIEWS OF QOL DATA

The data from these interviews generated three main categories—use of the individualized QOL results during the consultation, views of the use of individualized QOL assessments in clinical practice, and factors to be considered in relation to the implementation of individualized QOL assessments in clinical practice.

Use of the individualized QOL results during the consultation: Most doctors *used the results to inform themselves* about the patient, although some had *discussed* the results with the patient. The discussion either revealed that the patient's current QOL was satisfactory or that it helped in the *detection of a problem* that, said Doctor 1, “hardly would have been captured otherwise.”

According to the doctors, the main reasons why the instrument was not used actively were *time pressure* and *uncertainty about how to apply it*.

Views of the use of individualized QOL assessments in clinical practice: Most doctors appreciated this systematic means of *monitoring their patients' QOL* over time and of *detecting patient's areas of concern*. They claimed that QOL aspects often are overshadowed by attention to medical aspects of the disease and treatment:

Doctor 3: You tend to forget these other things, like relations and physical activity and so on. So, this [the QOL assessment] becomes a new element that might lead to improved quality if you somehow focus on, and discuss with the patient, ways of taking care of a column that's too low [referring to the graphical presentation of the QOL results].

Some doctors emphasized that the instrument would give them a more complete picture of the patient. “It makes you focus on what the patient has in focus, and not other things that [doctors] may have in focus, so it becomes more of a common focus,” noted Doctor 4; this may contribute to a better concordance between the patient and the doctor.

Some doctors claimed that this intervention might save time, since it provides information in a systematic, time-effective way. One doctor appreciated the graphic presentation of the results, which makes such information easy to grasp:

Doctor 2: Well, I get this paper from the patient, take a quick glance at how the columns lie, and discuss that in relation to the patient's disease, treatment status and so on.

The physicians had some concerns about the use of individualized QOL assessments in clinical practice. Several doctors feared that the procedure would be *too time consuming* and lead to “information overload” when added on top of everything else they already have to take into account.

Factors to be considered in relation to the implementation of individualized QOL assessments in clinical practice: The doctors also provided ideas of issues to be considered in relation to the wider implementation of individualized QOL assessments in clinical practice. One doctor believed that there had to be

evidence of its effectiveness before the instruments were used widely. Several doctors also believed that more “hands-on” practice opportunities were needed to incorporate this way of working. A general slowness in changing old routines within the healthcare system was deemed to be a challenging barrier to implementing these tools.

Suggestions for the future development of the intervention included allowing the patient to complete the test at home and having the results transferred directly to the doctor’s computer before the consultation to prepare for a patient meeting.

Discussion

The patients’ and the doctors’ perceptions of individual QOL assessments were largely congruent. Both groups appreciated that use of the SEIQoL-DW allows for systematic detection of patients’ QOL-related concerns and gives the doctor a picture of the patient as a whole person. Additionally, the patients believed that instruments may allow them to express their own priorities and values in life, whereas the doctors emphasized the time-effectiveness with which these instruments provided information on patients’ QOL.

STUDY LIMITATIONS

Heterogeneity was sought with regard to patient characteristics; thus, a substantial share of the most central perceptions about the intervention according to patients with GI cancer and their doctors likely was identified. However, the qualitative sampling procedure made quantification of perceptions impossible. To determine the prevalence of different perceptions and the relationship between background factors and perceptions, quantitative methods must be used. Importantly, these perceptions were generated by patients and doctors at two university hospital wards within the Swedish healthcare system; generalization of the identified perceptions to other settings therefore may be limited.

All patients completed both the original SEIQoL-DW and the DR-SEIQoL-DW; thus, the perceptions generated pertain to combined use of the two versions. It became obvious during the interviews that the participants did not attribute their perceptions to use of either instrument but, instead, to completion of both. However, it would be interesting to compare the impact of administering either instrument separately with use of both. If the use of one version alone was proven sufficient, that intervention would be even more time-effective.

The adoption of the practice was not optimal. Although we were most aware of the importance of interactive education of the doctors²¹ and local ownership of the change²² in implementing new practices, we probably underestimated the magnitude of training and doctor involvement needed. In addition, the format of the SEIQoL-DW may be more difficult to grasp than is the more familiar scheme of standardized QOL instruments, implying that training and monitoring of the former may need to be more intensive. Nevertheless, the intervention was effective enough for participants to gain

sufficient experience and to have informed views on using SEIQoL-DW in clinical practice.

PATIENT EMPOWERMENT AND PARTICIPATION

Empowered patients take charge over their own health and their interactions with healthcare personnel, and active patient participation may be associated with better patient outcomes.²³ According to our results, individual QOL assessments may contribute to patient empowerment in two ways.

First, they encourage patients to reflect upon their situations and on important factors in life—and reflection is a prerequisite for self-awareness. Heightened self-awareness regarding values and needs may be important in achieving patient empowerment.²⁴

Second, simply providing the instrument indicates that a doctor is willing to listen to the patient. Patients are rarely given “space” to express their feelings and to initiate discussions during a consultation,²⁵ and healthcare personnel seldom ask questions that make patients feel that conversations about social and psychological problems are legitimate.²⁶ Further, both patients and doctors often dismiss psychological symptoms as a normal consequence of having cancer and tend not to act upon them.²⁷ In our study, this was exemplified by a patient who resigned herself to living with a problem until it was brought to the surface by the QOL assessment.

Thus, individualized QOL assessments may empower patients by stimulating their ability to reflect and by encouraging them to voice their concerns. This is in line with the conclusions from a review of patient-targeted intervention strategies to enhance patient participation in the consultation.⁷ According to the review, feedback of patient-reported outcomes to doctors is the most promising strategy, besides coaching and educational materials. Such evidence is based on standardized patient-reported outcomes, yet the authors hypothesize that individualized measures may provide an even more dynamic patient/physician interaction, since the patient’s values and priorities are considered.

DETECTING SENSITIVE PROBLEMS

Problems detected in our study primarily concerned patient sexuality. Sensitive concerns are the least frequently addressed issues confronted during the clinical encounter, even among patients having cancers that impact sexuality immediately. When asked questions about sexuality, healthcare personnel may feel embarrassed, may think it is not their responsibility to discuss such matters, or may lack knowledge and experience to deal with these issues or resources to provide needed support.²⁸ Often, however, a few reassuring words may relieve some fears and problems²⁹; when possible, referral to another specialist or member of the healthcare team may be advisable.

DIFFERENTIATION IN INSTRUMENT USEFULNESS AMONG PATIENTS

Patients believed that an individual in the later stages of the disease who lacks a social network and has problems in coping with the disease may benefit most from the intervention.

Patients' preferences for information and involvement may change as cancer progresses³⁰ and may vary according to such factors as age, gender, and educational background.³¹ The doctors, however, did not raise the issue of differentiation among patients; instead, they viewed QOL assessments as a screening procedure in which nonproblematic QOL results confirmed no pressing need for further attention.

LIMITED USE OF QOL INFORMATION

A belief that QOL measurements are unnecessary³² and reliance on clinical judgment³³ explain why many oncologists do not perform formal QOL assessments. In our study, however, the doctors clearly appreciated this systematic approach to QOL assessment—although several did not use the information that actively. For example, in one consultation involving sexual problems, both the patient and the doctor ignored the issue, and no action was taken. This confirms that one of the assumed mechanisms of the intervention—that patients and doctors readily act on detected problems—sometimes does not occur.¹²

This discrepancy between attitude and behavior in relation to use of QOL information is well acknowledged.³² Although QOL assessments are considered valuable by clinicians, and use of these instrument increases the detection of problems, little evidence suggests their impact on patient management,³⁴ even when they are used in the palliative care setting.³⁵ The tension between ideals and the limits imposed by the realities of today's healthcare milieu may contribute to a discrepancy between attitudes and behavior.³⁶

The patients in our study also stressed that the success of any healthcare intervention depends on physician interest. Patients may value the opportunity to take part in an intervention, yet a physician's active endorsement of patient participation in an intervention is needed for the tool to be effective.³⁷

TIME/RESOURCE CONSTRAINTS

Doctors often cite time and resource constraints as barriers to the implementation of QOL assessments^{32,33}; both patients and doctors mentioned these problems in our study. However, randomized, controlled studies using EORTC QLQ-C30 showed that discussions based on QOL data do not prolong the length of the consultation.^{10,11} Some doctors in our study acknowledged that this instrument provided QOL information in a timely fashion; they also appreciated the graphic presentation of the QOL data, which made the information easy to grasp.

Access to systematic information on QOL may make anamnesis easier during consultation, since doctors know which areas are going well or poorly and how questions should be focused. The time-effectiveness of the intervention is further enhanced by computer administration of assessments, which allows automated collection, storage, and analysis of data and real-time provision of results.³⁸

POTENTIAL ADVERSE EFFECTS OF THE INTERVENTION

Two patients feared that the intervention could lead to anxiety or other adverse reactions in some patients; however,

none of the patients was worried about experiencing such reactions. Fears of triggering strong emotions (eg, despair) are acknowledged as one reason that health professionals avoid eliciting patients' perceptions.²⁶ Completion of the SEIQoL instruments, however, has caused less patient-reported distress than has administration of the Sickness Impact Profile (SIP); a similar trend was noted with administration of the standardized Short Form-36 (SF-36).³⁹

COMPARISON OF THE SEIQoL-DW WITH OTHER STANDARDIZED MEASURES

Several perceived effects of using the SEIQoL-DW likely may be achieved equally well, or maybe even better, with use of standardized QOL instruments; however, some qualities seem to be pronounced. Due to its focus on patient-defined QOL, the SEIQoL-DW apparently can empower patients and allow them to be viewed as whole persons. In addition, the SEIQoL-DW allows individuals to raise any issues they consider to be important. Standardized instruments, on the other hand, limit patients to respond to predefined items, which may cause aspects important to a certain individual (eg, sexuality) to be missed as irrelevant issues are included. This fact alone may explain why patients rate the validity of the SEIQoL-DW higher than they do such standardized instruments as the SIP and the SF-36.³⁹

The focus on areas most important to patients also seems to encourage them to reflect more actively upon their life situations as they relate to their disease. When patients share such reflections with physicians, their preferences and priorities may become more clear, the physician/patient relationship may improve, and clinical decision-making may become better informed. Taking the patient perspective into account and encouraging patient activity impact patient satisfaction, adherence to treatment, and clinical outcomes.⁴⁰ However, the greater depth into patient perspective provided by the SEIQoL-DW also requires that the provider is sensitive to differences among individuals in revealing inner thoughts—and that some patients may not desire an active role in the consultation.⁴¹

Conclusion

This study suggests that combined administration of the SEIQoL-DW and the DR-SEIQoL-DW may represent a systematic means of stimulating patient-centered care in clinical practice. According to both patients and doctors, this approach facilitates detection of patient concerns and, in particular, empowers patients and allows them to be seen as whole persons. However, formal quantitative evaluation of the outcomes of these interventions must be accomplished before more widespread use of these tools is recommended. The hypothetical differences between individualized and standardized measures preferably should be tested in a head-to-head comparison between a standardized instrument (eg, the EORTC QLQ-C30) and the SEIQoL-DW.

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