

Design of a Renal-Dependent Individualized Quality of Life Questionnaire

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The aim of this study was to design a concise, focused questionnaire to measure individuals' perceptions of the impact of their renal condition on their quality of life, taking account of the importance of life domains relevant for the individual.

The design of the renal-dependent quality of life (RDQoL) questionnaire was based on that of the Audit of Diabetes Dependent Quality of Life (ADDQoL) diabetes-specific individualized quality of life questionnaire, which was influenced by patient-centered principles underlying the interview method of McGee et al. The questionnaires specify life domains, and the respondents rate personally applicable domains for the importance and impact of the renal condition.

Observation in eight U.K. renal clinics, together with 40 in-depth interviews with peritoneal dialysis, hemodialysis, and transplant patients, provided the basis for item selection for the RDQoL.

The results of the study were as follows: each of the 13 ADDQoL items was relevant and important for renal patients. Additional suggestions for items included physical appearance, dependency, freedom, restrictions of fluid intake, and societal prejudice.

In conclusion, unlike other quality of life measures, the RDQoL is an individualized questionnaire measure of the impact of renal disease and its treatment on quality of life. Face and content validity is established for adult renal patients, and the RDQoL is being further evaluated for research and clinical use.

Key words

Quality of life, end-stage renal disease, individual differences

Introduction

In a review of existing measures of quality of life used in studies of patients with end-stage renal dis-

ease, Welch (1) identified a wide variety of measures that have been used, including health status measures, symptom measures, stress measures, affect and well-being measures, and measures of social functioning, social support and social resources, as well as measures of the perceived quality of life. Few of the measures were designed for renal patients, and none allowed the patient to indicate which aspects of life were applicable to him/her and the relative importance of each aspect for his/her quality of life.

The value of assessing the individual's view of his/her own quality of life has been discussed in detail by Joyce (2), who has contributed to the development of an increasingly widely used interview method of measuring individual quality of life, the SEIQoL (the Schedule for the Evaluation of Individual Quality of Life) (3). The SEIQoL differs from the previous generation of quality of life measures, which have tended to impose definitions of good and poor quality of life, which may have been derived from the views of the researcher, health professionals, or even other patients but not by the individual respondent him- or herself. Usually ratings are elicited for a wide variety of aspects of life and the ratings then summed to provide an overall score that does not reflect the individual's view of each item's applicability to him/her or the importance of each aspect of life to his/her quality of life (4).

With the SEIQoL methodology, the interviewer elicits from the patient the five most important domains of life that determine his/her quality of life. The individual patient then rates each domain from "as good as it could possibly be" to "as bad as it could possibly be" to produce a bar chart with bars of varying heights for each domain.

The importance of each domain in influencing overall quality of life is then determined by presenting the individual with a series of bar charts with the bars labeled with the patient's five domain labels. For each of 20 such bar charts the patient is asked to judge what his/her overall quality of life would be

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given the particular pattern of domain ratings indicated on the bar chart. The 20 ratings are then subject to a process called judgment analysis and the importance of each domain for quality of life estimated together with the reliability of the individual's responses.

Although the SEIQoL methodology has recently been adapted to produce a short form of the interview procedure (5) which does not require complex analysis, the method requires an interviewer and is not designed to consider the impact of a particular condition on quality of life, but rather to elicit views about quality of life *per se*.

The philosophy underpinning the SEIQoL provided the framework for the design of a diabetes-specific questionnaire method of measuring individual quality of life: the Audit of Diabetes-Dependent Quality of Life (ADDQoL) measure. Initial interviews with people with diabetes were used to elicit domains of life important for quality of life that were affected by diabetes and included the question "If you woke up tomorrow and found that your pancreas was working properly and you no longer had diabetes, what effect would that have on your quality of life?"

Responses could be covered by 13 domains concerning work, social life, family life, friendships, sex life, holidays and leisure activities, travel, worries about own future, worries about future of others, motivation to achieve things, physical functioning, others fussing, and enjoyment of food.

The opportunity to indicate that a domain was "not applicable" was allowed for selected domains and, when used, that item was not included in the scoring. For all applicable domains, respondents rated the impact of diabetes on the domain and the importance of the domain for their quality of life. Importance ratings were scored from 0 for "not at all important" to 3 for "very important," while impact ratings were scored from -3 to +3 with a score of zero when respondents indicated that the particular domain of life would be "the same" if they did not have diabetes.

The format of the condition-specific domains is shown in Figure 1 with the scores assigned for each response option included. Impact ratings (-3 to +3) are multiplied by the corresponding importance rating to provide a score from -9 to +9 for each domain. Weighted scores for each applicable domain can then be summed and divided by the number of applicable domains to give a final score that varies

from the same minimum (-9) to the same maximum (+9) for all respondents. (See Figure 2.)

Two overview items were also included, one asking about quality of life *per se* and one asking about the impact of diabetes on quality of life as a whole. The ADDQoL has been used in two substantial pilot studies to evaluate preliminary psychometric properties (6) and has since been incorporated into several large-scale studies (e.g., Reference 7). There is a growing body of evidence for the value of the ADDQoL and interest in a modified version of the measure suitable for use with other patient populations, including those with end-stage renal failure. Both diabetes and renal failure are chronic conditions requiring lifelong management involving self-care regimens which can be very demanding, with marked effects on quality of life. Thus an instrument that measures the effects of diabetes on quality of life provides a useful starting point in designing a measure for renal patients.

During 1996, Baxter Healthcare sponsored initial qualitative work to modify several of the many psychological measures developed for use with people with diabetes (8) in order that they would be suitable for use with renal patients in clinical trials and/or in routine clinical use. The ADDQoL formed the starting point for the development of the Renal-Dependent Quality of Life measure (RDQoL). This paper describes the design process of the RDQoL and presents the items included in the new measure.

Method

Design of the questionnaire was informed by observation and discussion with staff and patients in eight U.K. renal units (Gloucester Royal Hospital, Leicester General Hospital, Edinburgh Royal Hospital, Queen Elizabeth Hospital in Birmingham, Charing Cross Hospital in London, Royal Berkshire Hospital in Reading, Manchester Royal Infirmary, and Middlesex Hospital in London) followed by in-depth interviews with patients in two of those units. Initial visits to the eight renal units provided opportunities for observing consultations in general nephrology, dialysis and transplant outpatient clinics, ward rounds, peritoneal dialysis training sessions, hemodialysis unit activities as well as discussions with staff (doctors and nurses in the fields of peritoneal dialysis and hemodialysis, and transplant nurses; one social worker; three psychologists; and one counsel-

Individualized Quality of Life Measure

A. If I did not have renal failure, my working life and work-related opportunities would be:

-3	-2	-1	0	1	2	3	
very much better	much better	a little better	the same	a little worse	much worse	very much worse	N/A
This aspect of my life is (please circle the answer that applies for you)							
very important		important		somewhat important		not at all important	

FIGURE 1 Format of the domain-specific items.

lor), inpatients and outpatients. Forty in-depth interviews were conducted with adult patients aged 22 to 79 in two of the units (Leicester, 21 patients; Reading, 19 patients).

Fifteen women and 25 men were included in the sample. Transplant (n = 13), peritoneal dialysis (n = 14), and hemodialysis (n = 13) patients were interviewed in both units in approximately equal numbers. The Reading unit refers patients elsewhere for transplant surgery and postoperative care during the life of the transplant. Most of the patients interviewed had experience of more than one form of treatment and several had experience of a failed transplant.

During the in-depth interviews, patients' experience of renal failure and its treatment was explored. Perceptions of the impact of the condition and its treatment on their quality of life were elicited with the question "If you woke up tomorrow to find that you had two functioning kidneys and no longer needed any renal treatment, how would that affect your quality of life?" Thereafter interviewees were

asked to complete items from the ADDQoL modified to be appropriate for renal patients and, as additional items were designed, these were completed by subsequent patients.

Results

All 13 of the ADDQoL items were found to be relevant and important to the majority of renal patients interviewed. However, in two instances it was found that items could be combined without loss of information. The two items concerned with social life and friendships became one item, as did the two items concerned with worries about own future and worries about the future of family and close friends. Thus in the RDQoL, 11 of the items corresponded to the 13 original ADDQoL items. The format of the items is as shown in Figure 1 with the wording "If I did not have renal failure..." replacing the wording "If I did not have diabetes..." The 11 domain-specific items derived from the ADDQoL and included in the RDQoL are as follows:

If I did not have renal failure:

- *My working life and work-related opportunities would be: (very much better — very much worse)
- *My family life would be: (very much better — very much worse)
- My friendships and social life would be: (very much better — very much worse)
- *My sex life would be: (very much better — very much worse)
- My holidays or leisure activities would be: (very much better — very much worse)
- The things I could do physically would be: (very much increased — very much decreased)
- Problems with traveling (either local or long distance) would be: (very much decreased — very much increased)
- My motivation to achieve things would be: (very much increased — very much decreased)
- My worries about my future and the future of others close to me would be: (very much decreased — very much increased)
- The extent to which people would fuss or worry about me too much would be: (very much increased — very much decreased)
- +My freedom to eat as I wish would be: (very much increased — very much decreased)

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Note

Not applicable options were provided for the three items marked with an asterisk. The food item in the ADDQoL was modified to correspond more closely to the wording of the newly designed drink item, marked + (see below).

An additional eight items were designed to cover domains of life reported to be affected by renal failure and its treatment and are worded as follows (response option anchors in parentheses):

If I did not have renal failure:

My physical appearance would be:	(very much better — very much worse)
*My spiritual/religious life would be:	(very much better — very much worse)
The way society at large reacts to me would be:	(very much better — very much worse)
My finances would be:	(very much better — very much worse)
My living conditions would be:	(very much better — very much worse)
My confidence in my ability to do things would be:	(very much increased — very much decreased)
My need to depend on others for things I would like to do for myself would be:	(very much decreased — very much increased)
+My freedom to drink as I wish would be:	(very much increased — very much decreased)

Note: The not applicable option was provided for the item marked with an asterisk.

Two overview items, as in the ADDQoL, include an item concerned with quality of life *per se* derived directly from the SEIQoL (see A below in Figure 2) and an item concerned with the overall impact of renal failure on quality of life (modified from the ADDQoL) (see B below in Figure 2).

be sufficient to justify averaging of scores in the manner recommended for the ADDQoL. Any items that detract from the internal consistency would be scored separately or excluded from the developed questionnaire if responses indicated that an item is rarely considered to be of importance and/or influenced by renal failure. Subsequent studies will allow the RDQoL's sensitivity to change to be established in clinical trials. The newly designed instrument can be made available now to clinicians who would like to consider the clinical use of RDQoL in eliciting from individual patients the important life domains most

Conclusions and recommendations

The newly designed RDQoL is now ready for use in a large-scale data set to allow investigation of its psychometric properties (9). The internal consistency of responses to the 19 domain-specific items needs to

A. In general, my present quality of life is:

3	2	1	0	-1	-2	-3
as good as it could possibly be	very good	good	neither good nor bad	bad	very bad	as bad as it could possibly be

B. If I did not have renal failure, my quality of life would be:

-3	-2	-1	0	1	2	3
very much better	much better	a little better	the same	a little worse	much worse	very much worse

FIGURE 2 Format of overview items.

affected by renal failure with a view to informing efforts to improve quality of life perhaps by changing treatment modality, modifying dietary recommendations, or helping to provide access to other forms of support required, for example, to deal with sexual dysfunction or to facilitate holidays and travel.

The RDQoL, like the ADDQoL and the SEIQoL, focuses on applicable domains that are important to the particular individual. Unlike the SEIQoL, the RDQoL and ADDQoL are specifically concerned with the effects of a chronic condition and its treatment on quality of life. The ADDQoL was readily modified to be suitable for renal patients, although additional domains were identified as needed to cover the concerns of the renal patients for whom quality of life tended to be more seriously affected by their condition than was the case for many people with diabetes.

Forty percent of the population of renal patients also have diabetes, and the new items designed for the RDQoL will be considered for inclusion in the ADDQoL for evaluation in future work. The questionnaire forms of the RDQoL and ADDQoL provide a more accessible and less costly method than their predecessor, the SEIQoL. Because the RDQoL focuses on the impact of renal failure on quality of life rather than on quality of life *per se*, it focuses on outcomes that health professionals can help to improve, and it is likely to be more sensitive to change in clinical trials of interventions for renal patients.

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