

## Assessing psychological outcomes associated with diabetes

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The dominance of biomedical perspectives is a major obstacle to the assessment of psychological outcomes associated with diabetes management. Instead of being recognised as people who have lives to lead and other priorities in addition to their diabetes, people with diabetes are all too often treated like a collection of at-risk organs that need preserving at all costs and as a source of blood and urine for frequent monitoring of biomedical outcomes. If the creature illustrated in Figure 1 had a mouth, it might ask, "What about my quality of life?"

Comprehensive and easy to interpret measurements for psychological outcomes are no less complex than those for physical outcomes. Just as a profile of biomedical outcomes and processes is needed to monitor diabetes control and complications, a profile of psychological outcomes is also required. The first three items in the psychosocial dataset suggested in Table 1 are all outcome measures:

Table 1. Psychosocial dataset for diabetes management.

- Impact of diabetes on individuals' quality of life
- Psychological wellbeing
- Satisfaction with treatment
- Knowledge of diabetes and its complications
- Self-care skills

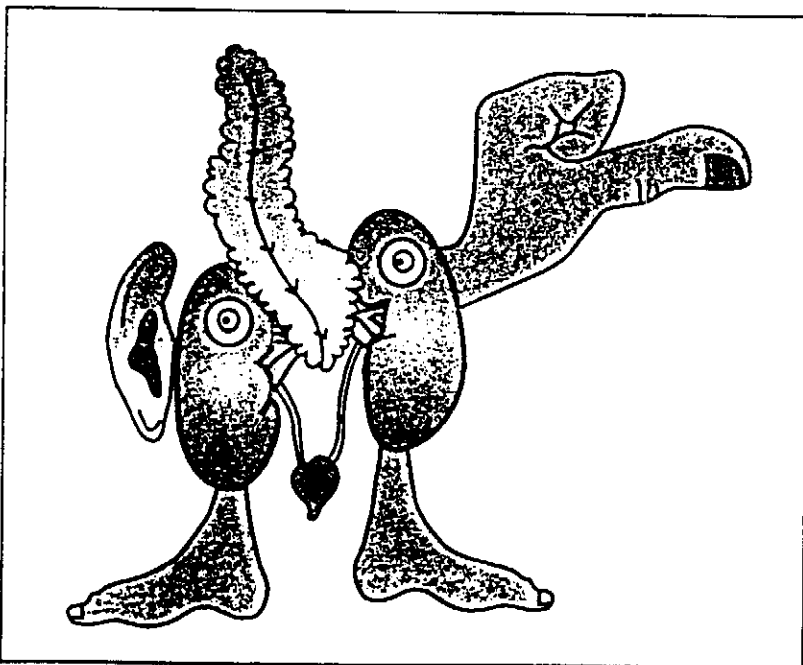


Figure 1. A biomedical perspective of a person with diabetes.

- The impact of diabetes on quality of life refers to an individual's perceptions of the effects of diabetes, in terms of how good or bad they feel their lives to be
- Psychological wellbeing refers to mood including positive aspects of wellbeing as well as depression and anxiety
- Satisfaction with treatment concerns the acceptability of a treatment regimen to the individual.

Problems may manifest in any one of these outcomes without being apparent in the other two. For example, a rigid, inconvenient regimen may impair quality of life but individuals who have no expectation of anything better may nevertheless declare themselves satisfied and retain a sense of psychological wellbeing. There would, however, be room for improvement in quality of life, and treatment modifications could achieve such an improvement.

The last two items in the suggested psychosocial dataset - knowledge of diabetes and self-care skills - help identify and deal with any deficits which may seriously impair outcomes, both physical and psychological.

Reliable research tools are available for all these psychosocial measures. Some are suitable for both research and clinical use. Measurement of the psychosocial impact of diabetes is as important and as complex an issue as measurement of blood glucose control or kidney function; few people have recognised the magnitude of the research task necessary to produce reliable and valid measures to meet all needs. Nevertheless, much valuable work has been done and was reviewed recently in the *Handbook of psychology and diabetes: a guide to psychological measurements in diabetes research and practice*.

### The need to measure psychological outcomes and processes

Medical colleagues still ask why it is necessary to measure quality of life in diabetes management - "Surely, if we take care of their physical problems, quality of life will improve as well?" This is true in some cases, for example when laser treatment of a damaged retina prevents blindness and thereby prevents associated deterioration in quality of life. Although the presence of severe complications of diabetes usually correlates with measures of quality of life, it does not follow that all medical and surgical interventions lead to improvements in quality of life.

In the wake of evidence from the Diabetes Control and Complications Trial (DCCT) on the benefits of intensified treatment in reducing the risk of retinopathy and other complications<sup>2</sup>, there has been renewed interest in improving diabetes control. If efforts are made to improve glycated haemoglobin (HbA<sub>1c</sub>) levels without



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simultaneously striving to improve or at least protect quality of life, there is a risk that reductions in HbA<sub>1c</sub> - if they are achieved at all - will only be obtained at the expense of patients' quality of life. It is possible to improve blood glucose control, at least for the duration of a clinical trial, using a demanding, rigid multiple injection regimen. Such a regimen may disrupt work and interfere with family life, and will be hard to maintain in the long term. As a result, not only will quality of life be damaged, but metabolic control will also be impaired. Success - in terms of blood glucose control - is far more likely if efforts are made to maximise quality of life and treatment regimens are tailored to suit individual patient's needs and priorities.

## Diabetes-specific scales

Health service managers and health economists want to compare quality of life in different groups of patients with different disorders, alongside other benefits and costs. If diabetes-specific outcome measures are used, comparisons with other patient groups are difficult. So why are generic measures, such as the ubiquitous SF-36, not recommended?

A psychologist new to diabetes would probably see no reason why generic instruments which measure health status, depression and other psychological states, should not be used with people who have diabetes. An understanding of diabetes and its management is necessary to appreciate the potential pitfalls of generic instruments. One drawback of generic measures is that different biomedical outcomes are relevant for different disorders, and the same applies to psychosocial outcomes. The experience of pain is a central concern for people with arthritis, but it is not an issue for most people with insulin-dependent diabetes for whom fear of hypoglycaemia may dominate. Measures designed specifically for people with diabetes can focus on issues which are especially important, avoiding irrelevancies. Thus diabetes-specific measures are likely to have greater sensitivity than generic measures.

The Wellbeing Questionnaire, designed and developed by my own diabetes research group and colleagues, does not appear to be diabetes-specific<sup>14</sup>; although, the items were selected with diabetes in mind. For instance, the depression sub-scale (originally constructed

elsewhere<sup>1</sup>) was selected because it does not include somatic items likely to be confounded with symptoms of poor diabetes control, eg weight loss, tiredness and loss of sex drive. Although somatic items, included in widely used instruments such as the Beck Depression Inventory<sup>15</sup>, may well be symptomatic of depression in the general population, in people with diabetes they may provide a proxy measure of diabetes control. The validity of an existing instrument must be reconsidered whenever it is applied to a new population for whom it was not originally developed. A new population includes not only different patient groups but also different cultural groups. Translated questionnaires need careful assessment<sup>1</sup>.

## Questionnaire selection

Scales can be explicitly diabetes-specific and can be shown to be reliable and valid in samples of people who have diabetes. However, they need to be selected carefully with the question to be answered borne in mind (Table 2). The data from the questionnaire also need to be analysed appropriately with an understanding of the nature of the questionnaire and its strengths and weaknesses. Just because a scale has been used by well-respected researchers in well-known studies such as the DCCT<sup>2</sup>, it does not necessarily follow that it will be suitable for another purpose.

The DCCT researchers reported that there were no differences in the mean total scores in the trial's quality-of-life questionnaires between the intensified treatment group and the conventional treatment group<sup>2</sup>. It is possible that intensified treatment may have had no impact on quality of life. However, considering the nature of the quality of life instrument used - the Diabetes Quality of Life (DQOL) measure - the lack of differences is more likely to be related to the way in which the DQOL data were analysed, which was too imprecise a method to reveal any effects of intensified treatment on quality of life<sup>1</sup>. Thus, even diabetes-specific questionnaires must be selected and analysed appropriately for the task in hand. This applies to all measures, not only to those of quality of life.

The diabetes knowledge (DKN) scales presented by Dunn and co-workers were designed and developed using specific populations in Sydney, Australia<sup>1</sup>. Some items travel better than others, and the suitability of

each item for the local context must be considered. The DKN scales also include dietary items which may not be appropriate to all cultures.

One way to evaluate a knowledge scale for use in a particular clinic is to give a copy of the questionnaire to all members of the diabetes team to see if they can agree on the correct answers. The local context - including the attitudes and behaviour of health care professionals

Table 2. Points to consider when choosing a questionnaire.

- Is it appropriate for my population of patients, judging from the appearance of the questions and my experience of the patients?
- Is it appropriate in my particular clinic?
- Is it appropriate given the views/behaviours of my diabetes care team?
- Has it been shown to be reliable with a similar population of patients?
- Is there good reason to think that it will be reliable with my population of patients?
- Is it likely to be sensitive to the changes I expect or hope to find?
- How will I handle the data generated and how will I inform patients about the use of the data?

and the availability of treatments and monitoring devices - may also be important in determining which attitudes and beliefs predict adjustment to diabetes.

Sometimes, existing instruments do not meet a particular need and new instruments have to be developed. My own research group is currently developing a short patient-centred questionnaire to assess impact of diabetes on quality of life. Influenced by the philosophy underlying the interview method of McGee and colleagues, the Schedule of Evaluation of Individual Quality of Life (SEIQoL)<sup>4</sup>, our new instrument - the Audit of Diabetes Dependent Quality of Life (ADDQoL)<sup>1</sup> - is designed to assess the perceived impact of diabetes on those domains of life which are relevant to the individual.

### Uses of psychosocial measures

Questionnaires may be used clinically to monitor psychological outcomes (eg satisfaction) and processes (knowledge) or to evaluate the effects of substantial changes to treatment (eg from tablets to insulin) or lifestyle (eg following a major job change).

Finally, questionnaires do not need to be given repeatedly to patients for the concepts measured to be clinically useful. By understanding the way a concept - such as quality of life or depression - has been reliably measured providing useful results, we can clarify our understanding of those concepts which are of value to all those involved in meeting the challenges of diabetes management.

### Conclusions

Questionnaire instruments to measure psychological outcomes and processes associated with diabetes management are potentially very valuable tools for diabetes research and clinical practice. Used appropriately, with recognition of the limitations of each instrument as well as the strengths, such tools have a central part to play in improving the quality of diabetes care.

For one psychologist's view on this article, see *Diabetes Dialogue* on page 12

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