

# What about quality of life?

*We now know that intensive treatment improves blood glucose control and reduces the risk of complications. But how does such treatment affect someone's quality of life? Many people with diabetes, their doctors and other health care professionals would like to know the answer, believes Dr Clare Bradley, Reader in Health Psychology at The Royal Holloway, Surrey*



As yet the only published information relating directly to this issue is a single sentence in the *New England Journal of Medicine* (DCCT Research Group, 1993): 'in addition, there were no significant differences in the mean total scores in the Trial's quality of life questionnaire, despite the added demands of intensive therapy'. The unwary reader may take this to mean that quality of life was not impaired by intensive insulin treatment. However, we need to look carefully at the measure and the way it has been used before drawing any conclusions from the results so far reported.

## **A new research tool**

The Diabetes Quality of Life (DQOL) measure was designed especially for this study and was the first research tool of its kind to measure diabetes-specific quality of life (Jacobson *et al.* 1994). The DCCT researchers recognised the

importance of measuring quality of life alongside blood glucose control. However, as with all measures, even measurements of blood glucose and HbA<sub>1c</sub>, we have to be aware of its strengths and limitations. The DQOL is no exception. Furthermore, even the best measures can be used inappropriately.

## **Used with care**

We cannot say from the DQOL results reported so far that intensive insulin treatment had no effect on the participants' quality of life; we only know about how participants in each group on average viewed their quality of life during the study. It is possible that some people found intensive treatment and the associated hypoglycaemia did reduce the quality of their lives in certain ways. But there may have been other ways in which the treatment or taking part in this study improved their quality of life. The DQOL measure can provide such information but the individual responses of the participants will need to be looked at more closely.

## **The DQOL measure**

The DQOL questionnaire included four categories of questions in which participants answered using 1 to 5 scales. The table opposite gives examples of the questions and comments on the responses which might be expected from participants receiving intensive

treatment and from those receiving conventional treatment.

## **Filling in the gaps**

Full results from the questionnaires have yet to be published by the DCCT researchers and we will not have a complete picture until we can look at responses to specific questions and consider the effects of the DCCT on individuals as well as groups. Such information would help other people who may be considering tightening their control.

## **Special care**

What needs to be remembered is that DCCT participants received special care while striving for tight control. They had enthusiastic health professionals keen to provide education, support and encouragement. They visited their diabetes centre every month and were in frequent telephone contact to review and adjust their regimens. Insulin was delivered by a pump attached to the body or by multiple injections, depending on the individual's preference and ability to achieve blood glucose targets.

**People considering tight control in the UK would need to ask themselves how their own circumstances compare with those research conditions and what facilities and support would be available to them.**

## Technology, diet and quality of life

Innovations such as pen injectors and blood glucose meters have made diabetes management easier. However, many people say that the most demanding and tiresome aspect of their regimen is their diet. There are only two questions which specifically address dietary issues among the 45 DQOL questions. So even when diet is a major problem for someone, this is not likely to be reflected in total DQOL scores.

There are many people with diabetes, especially those with non insulin dependent diabetes who are, for example, going to great lengths to exclude all sugar or trying to eat at exactly the same times each day. Guidelines on diet have changed over the years. New insulins, injectors and pumps give far greater flexibility with diet without sacrificing good diabetes control. If you are finding the diet side of diabetes control a burden, it may be well worth reviewing what you eat and what you would like to eat with a dietitian experienced in diabetes.

## What affects your quality of life?

There may be other ways your quality of life can be improved. What aspects of your diabetes management impinge on your quality of life?

**Remember, these quality of life issues are not trivial. If your treatment regimen is more bother than it needs to be, you will feel less inclined to follow it effectively or try for better control. Discuss the irritations and inconveniences with your doctor or diabetes specialist nurse.**

## The importance of communication

Your doctor and other members of the diabetes care team need to

know what your needs and priorities in life are but they will only know if you tell them. You can help the health care professionals to help you by talking about the effects of diabetes on your quality of life. Health care professionals are becoming much more aware of protecting quality of life and you will help to strengthen that awareness by talking to them!

I predict that, once psychological outcomes, such as diabetes quality of life, are given full consideration alongside HbA<sub>1c</sub> measures, and health care professionals work with individual patients to achieve the best biomedical and psycho-

logical outcomes, benefits will be two fold. Not only will patients' quality of life be improved, but lower HbA<sub>1c</sub> levels will also be more readily achieved and maintained.

### References

1. Diabetes Control and Complications Trial Research Group (1993) The effect of intensive treatment of diabetes on the development of progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine* 329, 977-986.
2. Jacobson, A M and the DCCT research group. (1994) The Diabetes Quality of Life measure. In C Bradley (ed.) *Handbook of Psychology and Diabetes: a guide to psychological measurement in diabetes research and practice*. Chur, Switzerland; Harwood Academic Press.

The Diabetes Quality of Life (DQOL) measure			
Subscale	Examples of questions	Response options	Expected differences between treatment groups
Satisfaction	<ul style="list-style-type: none"> <li>● "How satisfied are you with the time it takes to determine your sugar level?"</li> <li>● "How satisfied are you with your knowledge of diabetes?"</li> </ul>	five-point scale "very satisfied" to "very dissatisfied"	Patients in the intensified treatment group may well feel dissatisfied about time taken up with blood testing while feeling more satisfied with their knowledge of diabetes. Differences may thus be averaged out.
Impact	<ul style="list-style-type: none"> <li>● "How often do you have low blood sugar?"</li> <li>● "How often does diabetes interfere with your family life?"</li> </ul>	five-point scale "never" to "all the time"	Patients on intensified treatment would be expected to feel that diabetes has more frequent impact on their lives than patients on conventional treatment.
Social Worry	<ul style="list-style-type: none"> <li>● "How often do you worry about whether you will be able to complete your education?"</li> <li>● "How often do you worry about whether you will be able to take a vacation or a trip?"</li> </ul>	five-point scale "never" to "all the time" plus additional "does not apply" option	Long-term worries might be greater for the conventional treatment group while worries due to concern about hypos would be expected to be more frequent in the intensive treatment group. No clear differences between groups would be expected.
Diabetes Worry	<ul style="list-style-type: none"> <li>● "How often do you worry that you will get complications from your diabetes?"</li> <li>● "How often do you worry about whether you will pass out?"</li> </ul>	as above for Social Worry subscale	Patients using intensified treatment had reason to worry more about hypos but might well worry less about complications. On average, no clear group differences would be expected.