

Are blood glucose control and quality of life related?

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ARTICLE POINTS

1 Quality of life is a difficult concept to define — there is a lack of consensus in the literature as to what it is.

2 There are methodological problems with many quality of life studies.

3 There is conflicting evidence about whether there is a relationship between quality of life and metabolic control.

4 More rigorously designed research needs to be undertaken in relation to diabetes and quality of life.

KEY WORDS

- Quality of life
- Metabolic control
- Measurement tools

Introduction

It seems to be a reasonably common notion among healthcare professionals that good diabetes control, determined by a normal, or near normal, glycosylated haemoglobin (HbA_{1c}) level, ensures that people with diabetes have an improved quality of life (QoL). This article examines this assumption; some of the literature is briefly reviewed, as is the concept of QoL; the quality of QoL studies is discussed, and conclusions about whether the assumption is accurate are drawn.

There is now very strong evidence that a normal or near normal blood glucose level reduces the risks of developing diabetes complications (Diabetes Control and Complications Trial (DCCT), 1993; United Kingdom Prospective Diabetes Study (UKPDS), 1998). Both the DCCT (1996) and the UKPDS (1998) examined the effect of improved diabetes control on individuals' quality of life (QoL) and came to the conclusion that there was no significant impact, either positively or negatively. However, these results need to be interpreted with caution; for example, the instruments used to measure QoL may not actually be measuring that concept. Also, improved diabetes control not having a significant impact on QoL does not necessarily mean that it is associated with a 'good', or improved, QoL.

As well as these two major studies, which examined QoL as a secondary outcome, there are also several other studies exploring QoL and diabetes control which need to be considered.

What does the literature reveal?

Ingersoll and Marrero (1991) affirm that it is often assumed that maintenance of long-term blood glucose control and the concomitant reduction in diabetes complications leads to improved QoL in people with diabetes. Although there is some evidence to support this viewpoint (Gafvels et al, 1993) there is also an alternative perspective. Kiln (1995), for example, argues that the delay in onset of retinopathy for a year or two is not

justified by a twenty year reduction in QoL and no social life.

Many studies which explicitly endeavoured to examine correlations between QoL and diabetes control found no relationships. For instance, Pecoraro et al (1986) using the Sickness Impact Profile and The Health Perception questionnaire, found there was no significant relationship between glycaemic control and variations in health status. Similarly Hornquist et al (1990), investigating the effects of changing from syringe use to a pen regimen, found that using the pen improved QoL for the majority of patients. However, only those patients whose insulin regimen changed from one or two injections had improved diabetes control; hence, the authors concluded that there seemed to be no relationship between improved metabolic control and QoL. In a similar study, Tallroth et al (1990) compared a multiple injection insulin regimen (four injections a day), with and without a pen device, to thrice daily injections using a syringe. They concluded that the q.d.s. regime and probably the pen were responsible for the increased experience of well-being. However, glycaemic control did not improve in their group of patients. The study of Hanestad et al (1991), which had the specific aim of analysing the association between self-assessed satisfaction with life and glycosylated haemoglobin, concluded with the statement that there was no such relationship, although there were some associations with specific domains of the QoL instrument used. Similarly,

Wallymahmed et al (1992) found there was no relationship between perceived QoL and HbA_{1c}, using the DQOL, the QoL instrument devised for the DCCT (1993).

Karlson and Agardh (1994) undertook a very similar study to that of Tallroth et al (1990), which resulted in a similar outcome: multiple injection therapy improved QoL, but there was no improvement in diabetes control. Weinberger et al (1994) examined QoL in people with type 2 diabetes, using the SF36, a commonly used health status instrument. They also concluded that there was no relationship between glycosylated haemoglobin and the SF36 scores. A year later, Weinberger et al (1995) examined the impact of a nurse-coordinated intervention in primary care on QoL and glycaemic control. In this study the latter was improved, but there was no effect on QoL. Aalto et al (1997) also found that health related QoL was not related to glycaemic control.

In many of these studies, QoL improved as a result of the intervention being investigated but metabolic control did not, and in others metabolic control improved but QoL did not! Other studies seem to indicate that metabolic control is actually detrimental with regard to QoL. Naess et al (1995), in a population study of 75 000 people, concluded that psychological well-being was significantly related to HbA_{1c}, with a low result (good from the metabolic perspective) leading to low well-being scores and high HbA_{1c} giving rise to high well-being scores. This indicates that good diabetes control is not conducive to a high QoL. Similarly, Wikblad et al (1990), although not assessing QoL per se, found that good diabetes control was associated with a more negative attitude to diabetes. Wikby et al (1993a;1993b), when analysing change in QoL over time, concluded that people with poorer metabolic control actually rated their QoL higher.

In contrast, Hanestad (1993) found that higher HbA_{1c} was associated with decreased satisfaction with the physical and activity life domains of Hornquist's (1982; 1989) QoL package. This supports the results of her 1991 study (Hanestad and Albrektsen, 1991) in which females reporting more difficulties adhering to their diabetes regimens, and having lower QoL, were found to have

higher HbA_{1c} than those who had fewer adherence problems. Eiser et al (1992), using an adapted DQOL, also found that a lower fructosamine level was associated with a higher satisfaction with life with diabetes in a sample of young adults.

On the basis of data from these studies, it appears that the majority of investigators have found no relationship between metabolic control and QoL. Although some have found that 'good' control is related to a 'good' QoL, others have concluded that the relationship is inverse, i.e. good diabetes control is detrimental from a QoL perspective, affirming Kiln's (1995) view.

It is apparent that much further work needs to be undertaken to explore this issue. However, the apparently confusing situation about the relationship, or lack of it, between QoL and metabolic control may be caused by methodological differences and flaws in the studies undertaken.

The problem with the concept

One of the problems in performing QoL research is the lack of consensus about the concept itself. The major difficulty with identifying the characteristics of QoL is that it is a construct, or a concept, which has general meanings as a result of very high levels of abstraction (Burns and Grove, 1993). These highly abstract concepts are, according to Chinn and Kramer (1995), constructed from other concepts, which in the case of QoL, are often themselves not well defined, for instance, well-being and satisfaction (these conceptual difficulties probably explain why the terms 'well-being' and 'life satisfaction' are frequently used as synonyms for QoL). Thus, there is apparent confusion about the concept of QoL. Stewart (1992) partly attributes this confusion to a lack of clarity in distinguishing between what QoL *is* and what *contributes* to it.

Burns and Grove (1993) state that any concept, or variable, in a study requires both conceptual and operational definitions, the former providing the theoretical meaning — what QoL *is*. Gill and Feinstein (1994) suggest that, as there is no consensus about the meaning of QoL, or its components, researchers should at least describe what they perceive it to be. Many studies

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1 Many studies show no relationship between quality of life and metabolic control.

2 Other studies show that metabolic control is detrimental to quality of life.

3 Yet further studies demonstrate that metabolic control contributes to quality of life.

4 There are many methodological differences and flaws in qualitative quality of life studies.

exploring diabetes and QoL unfortunately fail to offer these conceptual definitions or descriptions, thereby making it difficult for the reader to assess exactly what concept is being measured, as there is no basis to judge the suitability or otherwise of the instruments chosen to measure the phenomena of interest (Gill and Feinstein, 1994).

Operational definitions, however, are provided in most of the studies discussed above. These definitions result from a set of operations or procedures to be utilised in measuring the concept or variable in question (Burns and Grove, 1993), and may provide clues about how researchers view the concept. However, Gill and Feinstein (1994) add a note of caution, suggesting that it is inappropriate to make assumptions about the meaning of QoL in a particular study on the basis of operational definitions. The reason is that many QoL instruments are used for a variety of purposes; hence, it is unsafe to assume that QoL can be adequately

defined in a particular study simply from a description of what that tool measures.

An example illustrates this point: the SF36 has been described as a QoL instrument (Jacobson, De Groot and Samson, 1994), a measure of generic health status (Bowling, 1995) and a health-related QoL tool (Weinberger et al, 1994; 1995). Functional status, health status, quality of life and health-related quality of life are all terms used in the literature somewhat indiscriminately and as synonyms for one another. It seems evident that the advice offered by Gill and Feinstein (1994) is essential: if researchers describe their understanding of the terms they use, the reader can make sense of their study.

Researchers also face another problem: the lack of consensus about what QoL is and what its components are — crucial pieces of information when measuring QoL — means that there is no 'gold standard' QoL instrument which can be used in all studies (and allow direct comparison between them). The studies discussed above used many different instruments (*Table 1*) and it is therefore not surprising that a firm conclusion about the relationship, or otherwise, between QoL and HbA_{1c} cannot safely be reached.

Reliability and validity

As well as difficulties with the concept of QoL, there are also some methodological problems evident in the diabetes related QoL literature, particularly in relation to the reliability and validity of the results obtained.

Validity refers to the extent to which an instrument actually measures what it is supposed to be measuring (Guyatt et al, 1993). The validity of an instrument in one situation does not necessarily ensure that it is valid in another. Rather, the assessment of validity is an ongoing process and ideally should be undertaken in every study in which the instrument is used.

It is somewhat disturbing, therefore, that in many of the studies discussed above, instrument validity was not determined. Consequently, as many of the existing instruments had not been revalidated in individual studies, and many newly developed tools had not been adequately validated initially, many of the results of these QoL

Table 1. Instruments used in the studies

| Study | Instruments used |
|-------------------------------|---|
| Hornquist et al, 1990 | Quality of life package |
| Wikby et al, 1993a | Quality of life package |
| Wikby et al, 1993b | Quality of life package |
| Hanestad, 1993 | Quality of life package |
| Hanestad and Albrektsen, 1991 | Quality of life package |
| Hanestad et al, 1991 | Quality of life package |
| Wallymahmed et al, 1992 | Adapted diabetes quality of life |
| Eiser et al, 1992 | Adapted diabetes quality of life |
| Tallroth et al, 1990 | Mood adjective check list Experience of diabetes treatment |
| Karlson and Agardh, 1994 | Experience measures Distress measures |
| Weinberger et al, 1994 | SF36 |
| Weinberger et al, 1995 | SF36 |
| Aalto et al, 1997 | SF20 |
| Naess et al, 1995 | Questionnaire I Questionnaire II |
| Pecoraro et al, 1996 | Sickness impact profile Health perceptions questionnaire |

studies may be doubtful.

Reliability is concerned with how consistently the instrument being used measures the concept being investigated (Burns and Grove, 1993). The reliability of most QoL instruments is measured by assessing internal consistency, or the extent to which all the items in a tool are measuring the same construct (Burns and Grove, 1993).

Again, in many of the studies discussed above, reliability was not measured. Many authors intimated that the instrument they were using had been assessed for both validity and reliability and may have deemed this to be adequate. However, Burns & Grove (1993) state that it is necessary to test the instrument in each study in which it is used, to ensure reliability is satisfactory in other samples. Thus it can be seen that the results from certain studies may be dubious.

Discussion and conclusion

It would seem apparent that no firm judgements can be safely made about whether or not a relationship exists between QoL and metabolic control, although there are indications that there is no relationship. This difficulty in arriving at a conclusion is probably due, in part, to the plethora of instruments which have been used to measure the concept; this is illustrated by the fact that in the fifteen studies discussed above, which all professed to be studying QoL, twelve different instruments were reportedly used. Many researchers seem to choose the QoL measure they use at random and there are few justifications for their choices.

Another observation is that some investigators are not measuring QoL overall; many instruments used are health or functional status instruments, or those which deal with aspects, or domains, of QoL. It would seem appropriate that if researchers wish to examine specific aspects of health and disease, the instruments they use to do so should not be labelled QoL tools.

The rigour of many studies is also suspect as psychometric testing of existing instruments in fresh research settings, and with a different sample, is often not undertaken.

Until further work to clarify the concept of QoL and studies investigating the concept in the context of diabetes care are carried out rigorously, the results of existing

studies must be interpreted with caution. The assumption that improved diabetes control leads to a better QoL does not appear to be supported by the literature; however, the lack of methodological rigour in some studies makes this conclusion somewhat tentative. ■

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- 1 Reliability and validity data are missing in many studies.
- 2 Firm judgements on whether or not there is a relationship between metabolic control and quality of life cannot be made.
- 3 Quality of life measures appear to be chosen at random.
- 4 Some quality of life instruments are measuring health or functional status.

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