

Quality of life in adolescents with type 1 diabetes

Original article:

A short form of the Diabetes Quality of Life for Youth questionnaire: exploratory and confirmatory analysis in a sample of 2,077 young people with type 1 diabetes mellitus. Skinner TC, Hoey H, McGee HH, Skovlund SE, for the Hvidore Study Group on Childhood Diabetes. *Diabetologia* 2006; 49: 621–8.

Summary and Comment:

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Summary

Over 2000 youth, 10–18 years of age, with type 1 diabetes were recruited in 18 countries across Europe, Asia and North America. Each participant completed the Diabetes Quality of Life for Youth (DQOLY) questionnaire. This questionnaire was originally published by Ingersoll and Marrero [1] as an adolescent version of the Diabetes Quality of Life (DQOL) measure developed for use in the Diabetes Control and Complications Trial (DCCT) [2, 3]. The DQOL is a 46-item diabetes-specific quality-of-life instrument consisting of four scales: satisfaction, impact, diabetes worry and social/vocational worry. Each item is rated on a five-point Likert scale. The DQOLY is very similar, consisting of 52 items, also rated on a five-point Likert scale, comprising three scales: impact of diabetes, worries about diabetes and satisfaction with life.

The purpose of this study was to examine the construct validity of the DQOLY in a large international sample of youth with type 1 diabetes. Because 14 languages were used, the DQOLY had to be translated and back-translated to assure equivalence of items across countries. All of the participants also had their glycemic control assessed by a blood assay for HbA_{1c} measurement at a central laboratory.

Because of the large sample size, the authors were able to use sophisticated statistical analytic techniques to evaluate the validity of the DQOLY. They divided the total sample in half, randomly selecting half of the sample for the

first dataset and retaining the responses from the remaining participants for a second dataset. This permitted the authors to carry out an exploratory factor analysis on the first dataset and then apply confirmatory factor analytic techniques to the second, independent dataset.

The exploratory factor analysis was used to look for underlying structures or factors in the data that met the criteria for a simple structure: items loaded >0.4 on only one factor and the item loadings were theoretically coherent. A four-factor and a six-factor solution were identified. Both solutions included: a satisfaction factor, a future worries factor and a parental control/concern factor. In the four-factor solution, the impact items loaded on a single factor. In the six-factor solution, the impact items were separated into three factors: impact of treatment, impact of symptoms and impact on activities. The four-factor model provided the most consistent explanatory model across all age groups (10–13, 13–15 and 15–19 years).

Next the authors conducted a confirmatory factor analysis using the second dataset. First they tested the factor structure proposed by the scale's originators. Next they tested both the four- and six-factor solutions obtained from their exploratory factor analysis. Only the six-factor model met criteria for goodness of fit, meaning that it provided a reasonably good description or explanation of the underlying structure of the second dataset.

The study's findings support some aspects of the original DQOLY scales: factors representing diabetes worry, impact of diabetes and satisfaction with life were all confirmed. However, a parental control/concern factor emerged that was not originally proposed on the DQOLY. The analysis also permitted the identification of poor or redundant items, permitting a shortened version of the questionnaire to be developed. The short form (DQOLY-SF; see *Table 1*) had good internal consistency across countries; the future worries scale, as well as the impact of symptoms and impact on activities subscales, were all significant predictors of HbA_{1c}.

Comment

Good quality of life is a primary goal of patient care. Our emphasis on tight diabetes control to avoid the long-term complications of the disease

Table I: DQOLY-SF items by scale.

Impact scale
Impact of treatment subscale
How often do you feel pain associated with treatment for your diabetes?
How often does your diabetes interfere with your family life?
How often do you feel restricted by your diet?
Impact of symptoms subscale
How often do you feel physically ill?
How often do you have a bad night's sleep?
How often do you miss school because of your diabetes?
Impact on activities subscale
How often do you find your diabetes limiting your social relationships and friendships?
How often does your diabetes keep you from driving a car or using a machine?
How often does your diabetes interfere with your exercising?
How often do you find your diabetes interrupts your leisure time activities?
How often do you feel your diabetes prevents you from participating in school activities?
Future worries scale
How often do you worry about whether you will get married?
How often do you worry about whether you will have children?
How often do you worry about whether you will not get a job you want?
How often do you worry about whether you will pass out?
How often do you worry about whether you will be able to complete your education?
How often do you worry that your body looks different because you have diabetes?
How often do you worry that you will get complications from your diabetes?
Parent control/concern scale
How often do you find that your parents are too protective of you?
How often do you feel that your parents worry too much about your diabetes?
How often do you feel your parents act like diabetes is their disease, not yours?
Satisfaction scale
How satisfied are you with the amount of time it takes to manage your diabetes?
How satisfied are you with the amount of time you spend getting check-ups?
How satisfied are you with the time it takes to determine your sugar level?
How satisfied are you with your current treatment?
How satisfied are you with the flexibility you have in your diet?
How satisfied are you with the burden your diabetes places on your family?
How satisfied are you with your knowledge of your diabetes?
How satisfied are you with your sleep?
How satisfied are you with your social relationships and friendships?
How satisfied are you with your work, school, and household activities?
How satisfied are you with the appearance of your body?
How satisfied are you with the time you spend exercising?
How satisfied are you with your leisure time?
How satisfied are you with life in general?
How satisfied are you with your performance in school?
How satisfied are you with how your classmates treat you?
How satisfied are you with your attendance in school?

reflects our efforts to protect our patients' quality of life in the future. At the same time we recognize that treatments so onerous that they degrade a patient's current quality of life are unlikely to be accepted or followed. Quality of life is important to both patients and providers and yet the measurement of this core concept has not always received the attention it deserves. Certainly the DCCT Study Group took an important step in developing a measure of dia-

betes-specific quality of life and the authors of the DQOLY are to be commended for adapting this for use with adolescents. However, measures typically evolve over time as data inform research and psychometrically improved versions are developed and tested. Some 15 years have passed since the publication of the DQOLY and, although a number of authors have used it [4–6], the measure itself has received little psychometric attention. Perhaps this is understandable

since investigators' research focus is typically on links between quality of life and a variety of interesting study variables rather than the psychometric quality of the DQOLY measure *per se*.

The article by Skinner et al. is refreshing because it moves the measurement of quality of life in adolescents with type 1 diabetes forward in some very important ways. Use of the DQOLY measure with such a large international sample is critically important, since much of type 1 diabetes research is now being done in international trials. The care taken to translate and back-translate the measure into 18 different languages is commendable and ready access to these translations will be important to all investigators interested in this important topic*. The authors also provide evidence of the reliability of the impact, future worries and parental control/concern scales across all 18 countries.

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The study's findings can also provide guidance to those who wish to further improve the measure. For example, impact seemed to be comprised of three subscales: impact on activities, impact of treatment and impact of symptoms. The internal consistency of these subscales was less than ideal ($\alpha = 0.47-0.65$), probably due to the small number of items comprising each subscale. Future studies could attempt to enhance the reliability of these subscales by adding and testing items or could examine whether the measurement detail offered by these subscales contributes something more than an overall impact scale.

The authors argue that the satisfaction scale might be dropped entirely from the DQOLY-SF, because it is not clear whether it is a diabetes-specific or general measure of quality of life. Disease-specific quality-of-life measures are often preferred since they are considered more sensitive to quality-of-life changes within a specific patient population. However, general quality-of-life measures remain important particularly in studies that include healthy and ill patients with a variety of medical disorders. Although the authors present a cogent argument for dropping the satisfaction scale altogether, a more cautious approach would

be to conduct additional studies examining the relationship between the DQOLY-SF satisfaction scale and other general measures of quality of life. This additional information could further inform the decision to delete or retain this scale.

The emergence of a parental control/concern scale from the analysis is particularly interesting. This three-item scale was remarkably reliable across countries and is of considerable interest given the adolescent population under study. The authors sometimes refer to this scale as a parental control scale and at other times as a parental concern scale. The scale's three items seem to represent both parent concern and control, which might explain the authors' interchangeable use of these terms; future studies are needed to clarify the underlying construct represented.

Adolescence is a time of increasing independence; conflict between young people and their parents often arises over many aspects of adolescents' lives including their diabetes care. A number of studies have suggested that transfer of diabetes management responsibilities to the adolescent too early may interfere with diabetes control [4, 7-10]. The DQOLY scale could prove particularly useful as we attempt to identify ways in which parents and providers can help young people emerge as successful managers of their own diabetes.

References

1. Ingersoll GM, Marrero DG. A modified quality of life measure for youths: psychometric properties. *Diabetes Educ* 1991; 17: 114-20.
2. DCCT Research Group. Reliability and validity of a diabetes quality-of-life measure for the Diabetes Control and Complications Trial (DCCT). *Diabetes Care* 1988; 11: 725-32.
3. Jacobson AM, de Groot M, Samson JA. The evaluation of two measures of quality-of-life in patients with type I and type II diabetes. *Diabetes Care* 1994; 17: 267-74.
4. Grey M, Boland EA, Yu C et al. Personal and family factors associated with quality of life in adolescents with diabetes. *Diabetes Care* 1998; 21: 909-14.
5. Lawson ML, Cohen N, Richardson C et al. A randomized trial of regular standardized telephone contact by a diabetes nurse educator in adolescents with poor diabetes control. *Pediatr Diabetes* 2005; 6: 32-40.
6. Wagner J, Heapy A, James A, Abbott G. Glycemic control, quality of life, and school experiences among students with diabetes. *J Pediatr Psychol* 2006; 31: 764-9.
7. Follansbee DS. Assuming responsibility for diabetes management: what age? what price? *Diabetes Educ* 1989; 15: 347-53.
8. Fonagy P, Moran GS, Lindsay MK et al. Psychological adjustment and diabetic control. *Arch Dis Child* 1987; 62: 1009-13.
9. Wysocki T, Taylor A, Hough BS et al. Deviation from developmentally appropriate self-care autonomy. *Diabetes Care* 1996; 19: 119-25.
10. Holmes CS, Chen R, Streisand R et al. Predictors of youth diabetes care behaviors and metabolic control: a structural equation modeling approach. *J Pediatr Psychol* 2006; 31: 770-84.

* Translated versions of the DQOLY-SF may be obtained from Dr Soren Skovlund at sesk@novonordisk.com