Longer Life Foundation – Final Project Report

Project Title: *Health-related Quality of Life: A strategy for improving physician-patient communication and patient outcomes*
Investigator: Thomas Burroughs, PhD and Radhika Desikan, PhD
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Abstract

Objective: To design and test the reliability and validity of a shortened version of the Diabetes Quality of life questionnaire.
Research Design and Methods: 498 participants with Types I or II diabetes completed the DQOL, a measure of current diabetes self-care behaviors and a measure of demographic and health characteristics. A 3-stage statistical process identified the underlying structure of the DQOL and the items from within each DQOL component that were most predictive of self-care behaviors and satisfaction with diabetes control.
Results: Principal components analysis identified 5 key underlying factors in the DQOL. Best subset regression analysis identified a set of 12 questions that best explained self-care behaviors and satisfaction with diabetes control. Subsequent regression analyses found that the 12-item scale was as effective at predicting self-care behaviors (Shortened Scale R^2=.225, Full Scale R^2=.207) and satisfaction with diabetes control (Shortened Scale R^2=.533, Full Scale R^2=.527) as was the full DQOL.
Conclusions: The 12-item DQOL Short Form provides a vehicle for assessing health-related quality of life in a physician office setting in order to identify quality of life issues that might not arise during the typical patient-physician encounter. The shortened instrument was able to predict self-reported diabetes care behaviors and satisfaction with diabetes control as effectively as the full version of the instrument.

Lay Summary

Quality of life is becoming an increasingly important outcome for healthcare providers and researcher. As scientists continue to develop advanced ways of caring for patients, our ability to extend length of life is enhanced, but the quality of this extended life is often at question. This issue is particularly pertinent for patients with chronic illnesses, such as diabetes. Past research has developed instruments to assess the quality of Often the medical interventions themselves pose significant physical, logistical and functional problems for patients. Past research

Introduction / Brief Literature Review

The past few decades have witnessed considerable research about health-related quality of life (HRQOL), leading to the development and refinement of a number of generic and disease-specific health-related quality of life measures [1-8]. A patient's quality of life – one's total physical, mental, and social well-being — has come to be viewed as a critical outcome of disease treatment and control. Consequently, generic and disease-specific health-related quality of life measures have been used extensively in clinical trials and research initiatives to assess the impact of medical interventions [2, 3, 9].

A finding underscoring the importance of HRQOL is that clinical variables alone do not comprehensively capture a patient's perception of their health. In fact, studies show relatively low correlations between clinical measures of disease activity (e.g., peak flow rates for asthma and glycated hemoglobin results for diabetes) and patient's perceptions of health and well-being [5, 10]. Such low correlations have been reported in several chronic diseases including diabetes, asthma, and chronic obstructive pulmonary disease [9, 11-13].

The issue of health-related quality of life is particularly important for diseases such as diabetes where the health care regimen requires ongoing self-care behaviors that can interfere with patients' desired lifestyles. Providing optimal diabetes care involves recognizing the inherent cost - benefit trade-off between the disease

and treatment burden. The Diabetes Control and Complications Trial (DCCT) hinted at this delicate balance by finding that intensive insulin therapy yielded a significant reduction in diabetic complications compared to traditional insulin therapy [14], but did not lead to improved quality of life [15]. Other research has yielded inconsistent relationships between therapy intensity and quality of life [16-26] due, in part, to the fact that health-related quality of life is influenced by a myriad of other factors such as the existence of other health problems, social relationships, marital status, [7, 22, 27], patient knowledge [28], treatment satisfaction [18] and perceived ability to control one's disease [7].

For the health care professional, a key goal in treating diabetes is to help patients improve their quality of life by identifying and addressing diabetes-related issues. Past research has found, however, that as much as 54% of patient problems and 45% of patient concerns are neither elicited by the provider nor disclosed by the patient during a typical office visit [29]. Along these same lines, patients often express dissatisfaction with the information provided to them by their providers [29-30], and this patient-provider communication is linked to patient compliance with therapy [31] and satisfaction with care [32-33]. Findings also suggest that improving patient-provider communication benefits patient health and promotes provider loyalty as a consequence of improved satisfaction with care [34].

Methods

First, the literature was reviewed for diabetes-specific quality of life measures and these instruments were reviewed for comprehensiveness and psychometric properties. Based on this review, the DQOL was selected to be our foundation instrument. Second, a panel of experts in diabetes care reviewed the DQOL for comprehensiveness. Third, this instrument along with a measure of current health care behaviors and demographic characteristics was administered to 1,080 adults with type 1 and 2 diabetes. Fourth, this data was analyzed to identify those survey items that best predict regimen adherence and satisfaction with the diabetes regimen. These items became the core of the shortened DQOL instrument. Lastly, analysis was conducted to evaluate the statistical performance of this shortened instrument.

Results

Sample Characteristics

Of the 498 respondents, 32% had type 1 diabetes, and 68% had type 2 diabetes. Length of time since diagnosis ranged from 1 to more than 20 years, with the median length of time between 6-10 years. Slightly more than half the respondents were female (53%), and ages for respondents ranged from 21 to more than 80 years, with the median of 51 years. Educational levels ranged from a completed doctoral to less than a high school degree, with 41% having completed just a high school degree. Annual household income ranged from less than $15,000 to more than $100,000, with a median of $37,500. In examining respondents' health status, subjects reported a number of health problems including hypertension (51% of subjects), high cholesterol (45.3%), arthritis (42.4%), sleeping problems (44.6%), depression (33.3%).

Item Selection

We identified 26 items predictive of self-care and satisfaction with diabetes control. In stage 3, we used principal components analysis [56] to identify groups of items with overlapping content. This step yielded five significant principal components that accounted for 9.23-15.35% of the total item variance each, and 56.73% of the total item variance collectively. The solution demonstrated clean separation of components, with only 3 items demonstrating minor cross-loadings, and only 1 item failing to load with a correlation of at least .40 onto any component.

Type 1 Diabetes. Six items were identified by the two-stage regression analysis as predictors of satisfaction with diabetes control ($p < .0001$). These items included satisfaction with the time spent managing diabetes, satisfaction with current treatment, satisfaction with sex life, frequency of bad sleep, frequency of career limitation, and frequency of worry over missing work (Table 2 provides regression parameters).

Similarly, nine items were identified as predictors of self-care adherence ($p < .0001$). These items included satisfaction with glucose maintenance, satisfaction with current treatment, satisfaction with burden on family, satisfaction with exercise, frequency of pain with treatment, frequency of feeling ill, frequency of breaking diet to avoid telling others about diabetes, frequency of career limitation, and frequency of worry over passing out.

Regression analyses were next conducted to evaluate how well the 6- and 9-item models predicted satisfaction and self-care, compared to models containing all 60 DQOL items. In predicting satisfaction with treatment, the 6-item model had an adjusted R-squared of .562, compared to .580 for the 60-item model. In predicting self-care behaviors, the 6 item model had an adjusted R-squared of .360, compared to .254 for the 60-item model. These results suggest that 6- and 9-item solutions are effectively able to predict overall satisfaction with diabetes control and overall self-care behaviors as well as the full 60-item survey among type 1 diabetes.

Type 2 Diabetes. The results differed for type 2 diabetes. Six items were identified as predictors of satisfaction with diabetes control ($p < .0001$). These items included satisfaction with the time spent managing diabetes, satisfaction with checkups time, satisfaction with current treatment, satisfaction with exercise time, frequency of pain with treatment, and frequency of worry over passing out. Similarly, six items were identified as predictors of self-care adherence ($p=.0075$). These items included satisfaction with glucose maintenance, satisfaction with diabetes knowledge, satisfaction with exercise time, frequency of breaking diet to avoid telling others about diabetes, frequency of worry over missing work, and frequency of worry over passing out.

Regression analyses evaluated how well these 6-item models predicted satisfaction and self-care, as compared to models that contained all 60 DQOL items. In predicting satisfaction with treatment, the 6-item model had an adjusted R-squared of .513, compared to .492 for the 60-item model. In predicting self-care behaviors, the 6-item model had an adjusted R-squared of .117, compared to .196 for the 60-item model. These results suggest that, for type 2 diabetes, overall satisfaction with diabetes control was predicted as well by the 6- solution as the 60-item solution, though overall self-care behaviors were predicted slightly better by the overall 60-item model than by the 6-item reduced model.

Constructing the DQOL Short-form Clinical Inventory

These four sets of items (two each from type 1 and 2 diabetic analyses) were then combined into a master 15-item set (several items were significant in more than one of the previous regression models). A total scale score was calculated for this shortened scale based upon regression weights. The new inventory showed good internal consistency (alpha = .85). The new total score was correlated with the full DQOL scale and with the individual DQOL subscales. The uncorrected correlation between the two total scales was .81 and correlation corrected for attenuation due to the instrument's reliability was .91, suggesting that the shortened version was able to explain the vast majority of variation in total DQOL scores. Equivalent analysis suggested that the shortened scale correlated strongly with each of the individual subscales from the full instrument. The strongest relationship was with the satisfaction subscale (uncorrected r=.84 and corrected r=.97) and the weakest relationship was with the social worry scale (uncorrected r=.43 and corrected r=.52). The final set of 15-items selected into the two regression models is shown in the appendix.

Discussion

Research has suggested that individuals with diabetes have reduced health-related quality of life compared to the general population, but better health-related quality of life than individuals with many other chronic illnesses [7]. While intensive insulin therapy has been successful in achieving control of diabetes physical symptoms and complications, patients report varied and mixed impact on their health-related quality of life [17, 19-21, 23-24, 27]. As a result, helping patients balance disease control and treatment burden is a critical goal for healthcare providers. Past communication research has demonstrated that many patient issues go unexplored in office visits, due to factors including limited time for interaction, provider communication style, and patient discomfort raising issues with provider [25, 29, 31, 33, 34]. The goal of this study was to establish a reliable and valid brief DQOL inventory – focused on treatment satisfaction and compliance issues — that could be effectively integrated into the clinician office setting to improve patient-provider communication. Previous health-related

quality of life instruments, due largely to their length, have not transitioned from the research setting to the provider office setting.

To establish this shortened and treatment-focused inventory, we employed a statistically-driven 3-step process to identify the core set of items that is strongly linked to participants' satisfaction with the diabetes control and their own self-care behaviors. The result was a 15-item shortened scale instrument that is highly correlated with the total DQOL and subscales. The shortened instrument was also able to explain as much variance in self-care behaviors and satisfaction with diabetes control as did the full DQOL. This suggests that we lost very little core information from the original DQOL subscales as a result of significantly shortening the survey.
A primary purpose for this shortened survey is to facilitate better communication between patients and their healthcare providers. The 15 items on this survey cover a broad range of issues related to diabetes. They range from satisfaction with various aspects of the diabetes regimen to fears and concerns to frequency of diabetes problems. One can easily imagine how these issues might not be uncovered during a typical clinical office visit. It is also easy to imagine how many of these issues could be addressed either through tailoring of the regimen, providing information, or simply listening and providing reassurance to patient concerns.

Despite these limitations, this study established a 15-item shortened version of the DQOL that demonstrated excellent ability to predict satisfaction and self-care behaviors, particularly among patients with type 1 diabetes. The items on the instrument cover a wide range of issues for people with diabetes that are addressable during routine clinical care. By identifying issues that might not otherwise come up during clinical care, the instrument provides an opportunity to strengthen the provider-patient interaction and provide patients with assistance for issues that may be impeding their health-related quality of life.