Health-related quality of life and type 2 diabetes: A study of people living in the Bella Coola Valley

A survey and chart review were used to investigate associations between quality of life measures and diabetes-related factors, including duration of diabetes, blood sugar control, insulin use, and complications.

ABSTRACT:

Background: This study was undertaken to investigate the relationship between chart-derived clinical information and health-related quality of life scores for diabetics living in an isolated, rural Canadian community.

Methods: The investigators relied on a population-based retrospective chart review and a survey distributed by mail. Participants were adults with type 2 diabetes living in the Bella Coola Valley who had a chart at the Bella Coola Medical Clinic as of September 2001. All participants completed a detailed health-related quality of life survey between August and December 2001. The diabetesrelated information that was collected from charts included duration of diabetes, blood sugar control as measured by glycosylated hemoglobin, insulin use, and number and severity of complications. Healthrelated quality of life was measured using the 36-item Short-Form Health Survey and items from the Behavioral Risk Factor Surveillance System.

Results: The most prevalent diabetic complications were coronary artery disease (16%), retinopathy (15%), cerebrovascular accidents (9%), neuropathy (9%), peripheral vascular disease (7%), and nephropathy (6%). Most of these complications were assessed as being "minimal" to "moderate" in severity. Significant correlations were found between chart-specific information (duration, insulin use, complications) and many different healthrelated quality of life survey items. Improved blood sugar control was paradoxically associated with lower health-related quality of life domain

Conclusions: People with diabetes experience significant impairment in their health-related quality of life, which is associated with a variety of clinical parameters. The presence of diabetic complications significantly affects some health-related quality of life survey items.

Background

Health care providers should strive to understand the physical, emotional, and social impacts of having chronic disease. Theoretically, such patientcentred knowledge can be incorporated into chronic disease treatment strategies designed to improve or enhance function in everyday life and improve or enhance health-related quality of life (HRQOL). Improved HRQOL may also lead to fewer office visits and hospitalizations and hence reduce health care costs.1,2

With respect to diabetes, this means that health care professionals should not just focus on objective vital signs (e.g., blood pressure), physical examination findings (e.g., retinopathy, nephropathy, heart disease), and laboratory tests (e.g., glycosylated hemoglobin values) associated with treatment. Health care professionals should also strive to understand the subjective impact diabetes and its management

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have on diabetic patients' physical and mental functioning—that is, their health-related quality of life. Ideally, patients should have both improved glycemic control and better HRQOL.³

Studies have shown that HRQOL survey scores for diabetics are much lower than those reported for nondiabetics.1-8 The reason for lower scores for diabetics is probably multifactorial. Compared with nondiabetics, diabetics tend to be older; tend to be overweight; are less likely to exercise; are much more likely to have comorbidities (e.g., hypertension, coronary artery disease, hypercholesterolemia); and are more likely to suffer complications such as painful polyneuropathy, upper gastrointestinal symptoms, impotence, retinopathy, nephropathy, amputations, symptomatic hyperglycemia, and hypoglycemia. 1-4,6,9-23 All these things have been associated with lower health-related quality of life

We recently reported on healthrelated quality of life for residents living in the isolated, rural community of Bella Coola.24-26 Within the Bella Coola Valley population, age, Aboriginal status, and diabetes were all found to be associated with poorer selfreported health-related quality of life scores. Mean scores for Aboriginal people were lower/poorer than mean scores for non-Aboriginal people in all the quality of life questions. Mean scores for diabetics were also lower than mean scores for nondiabetics in all the quality of life questions. Aboriginal diabetics reported the worst scores of all on almost all of the quality of life questions. Bella Coola Aboriginal diabetics tend to have earlier onset of disease, and tend to have poorer blood sugar control compared with non-Aboriginal diabetics, so we wondered whether these parameters also affect HRQOL.27,28 The specific objective of our study was to investigate the

relationship between chart-derived diabetes-related clinical information (e.g., duration of diabetes, blood sugar control, insulin use, number and severity of diabetic complications) and HRQOL scores in Bella Coola diabetics.

distribute a health-related quality of life survey by mail.

The second chart review took place in the spring of 2003. Clinic charts of patients on the September 2001 clinic population list were reviewed for the following information: age, sex, and

Mean scores for diabetics were also lower than mean scores for nondiabetics in all the quality of life questions.

Methods

The Bella Coola Valley is an isolated rural community located in the central coast region of British Columbia. According to the 2001 census, 2285 people live in the Bella Coola Valley, and 46% of these people are of Aboriginal descent.²⁹ Bella Coola Valley is part of the traditional territory of the Nuxalk Nation, a tribe of Salish-speaking Coastal Indians.³⁰

This research project was carried out in a participatory fashion, following the recommendations outlined in a recently published policy statement. 31,32 Details of the consultation and ethics approval process used were reported elsewhere. 24-26

Chart review

Two retrospective reviews of clinic charts were conducted by Dr H. Thom - masen (HT). The first chart review was done in July and August 2001 to determine an "active" September 2001 clinic population. Names and addresses were tabulated using an electronic spreadsheet and these were then used to

Aboriginal status; smoking status, height, and weight; presence or absence of diabetes and other chronic conditions. Aboriginal status for the study population was determined from multiple sources: Nuxalk Bandlists, a locally available genealogy, the clinic chart, and the completed survey. 17,24,25,33 The diagnosis of diabetes was based on the 1998 clinical practice guidelines for the management of diabetes in Canada. 34

Once the diagnosis of diabetes was confirmed, the following information was also collected: date of diagnosis and duration of diabetes in years, most recent glycoslyated hemoglobin (HbA1c) level, diabetic management with respect to medications (oral hypoglycemic agents and insulin), and presence or absence of six possible diabetes-related morbidities (coronary artery disease, retinopathy, cerebrovascular accidents, neuropathy, peri pheral vascular disease, nephropathy). Within each of the six diabetes-related morbidities were four possible subcategories of disease severity: none (score

= 1), minimal (score = 2), moderate (score = 3), and severe disease (score = 4). A minimum score would be 6; that is, 1 (no disease) in any of the 6 morbidity categories (1 \times 6 = 6). Theoretically, someone could have a maximum score of 24; that is, 4 (severe disease) in each of the 6 morbidity categories $(4 \times 6 = 24)$. Details of this morbidity scoring system are described elsewhere.26

Survey

As part of a larger investigation, a health and health care survey was offered to all adults living in the Bella Coola Valley between August 2001 and May 2002.24 The aim of this investigation was to obtain some baseline self-reported data on the health status and overall quality of life of all residents of the Bella Coola Valley of British Columbia aged 17 years or older, and to measure the impact of a set of designated health determinants on their health and quality of life. An identification number was assigned to each questionnaire. A single investigator (HT) was the only one able to link this number to the 2001 clinic patient list. This information was used for the purposes of re-mailing, and for linking questionnaire responses to retrospective clinic chart review information. All recipients were asked to read an informed consent form or were read an informed consent form prior to completing a questionnaire.

The questions in the "General Health" section of the survey are from the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36).35-38 The SF-36 is one of the most widely used tools for assessing health-related quality of life. It is sometimes referred to as the "gold standard" for health status measurement and its norms for several populations provide useful benchmarks. The SF-36 scale works best as a health profile measure with eight

dimensions, rather than as a single summative measure. Questions in the eight health dimensions evaluate the degree to which an individual's health

- 1. Physical functioning
- 2. Social functioning
- 3. Bodily pain
- 4. Role limitations caused by physical health problems (Role/phy sical)
- 5. Role limitations caused by emotional problems (Role/emotional)
- 6. Emotional well-being (Mental health)
- 7. Energy/fatigue (Vitality)
- 8. General health perceptions

The SF-36 scores range from 0 to 100, with higher scores indicating better functioning, well-being, and state of health. Reliability and validity of the SF-36 have been demonstrated for both insulin-dependent diabetes mellitus patients and non-insulin-dependent diabetes mellitus (NIDDM) patients.35,39-41

Our survey also included eight questions from the Behavioral Risk Factor Surveillance System (BRFSS) devised by the US Centers for Disease Control and Prevention, which focuses on the number of healthy/unhealthy days experienced and special limitations on problems.²

Statistical analysis

Chart and survey-derived information was entered into an electronic spreadsheet. Names and addresses were removed from this linked data set. Results were summarized, graphs creat ed, and the data sent to statisticians and other researchers for further analyses. The data was analyzed using SPSS software.

First, the SF-36 questions were grouped according to the eight domains and then scored as directed by Ware and colleagues.35 Next, demographic characteristics of age, gender, and ethnicity were analyzed. After controlling for age, we considered the relationships between health-related quality of life variables and diabetes and/or Aboriginal status. The relationship between clinic chart information (duration of diabetes, insulin use, blood sugar control, diabetes-related complications) and HRQOL measures was then exam-

Differences between categorical data (e.g., sex, diabetic status) were evaluated using Pearson's chi-square test and differences between continuous data (e.g., age) were evaluated using one-way ANOVA tests. Significance was defined as P value $\leq .05$ for each outcome measure.42

Results

A total of 675 usable surveys were returned. Of these, 72 were from people with type 2 diabetes. Survey respondents did not answer all questions, so the number of responses varies from survey question to survey question. An estimated 1771 Bella Coola adult residents were eligible to complete this survey. An estimated 127 Bella Coola adult residents have type 2 diabetes mellitus. Therefore, the estimated overall response to the survey was 38% (675/1771); the estimated response rate for diabetics was 57% (72/127); and the estimated response rate for nondiabetics was 37% $(603/1644).^{25}$

Comparison of the diabetic survey population with the entire Bella Coola Valley diabetic population reveals no significant differences with respect to proportion of Aboriginal people (61% vs 55%: P = .41), proportion of women (51% vs 46%: P = .44), and average age (60.2 vs 59.9 years: P = .87). The rates for diabetes complications for the diabetic survey population were also similar to rates reported for the entire Bella Coola Valley diabetic population regarding coronary artery dis-

Scores (number answered question)												
	Physical functioning	Social functioning	Bodily pain	Role physical	Role emotional	Mental health	Vitality	General health				
Nondiabetic	83.1 (593)	79.2 (597)	66.4 (597)	70.5 (598)	77.6 (590)	73.9 (596)	57.0 (597)	69.5 (591)				
Diabetic	69.4 (64)	70.4 (65)	55.3 (64)	43.1 (65)	55.6 (63)	70.4 (64)	50.7 (64)	53.2 (64)				
Duration in years												
< 4.0	71.2 (21)	72.6 (21)	55.6 (20)	45.5 (22)	60.3 (21)	67.1 (21)	50.8 (21)	60.4 (21)				
4.0-8.9	74.2 (24)	64.1 (24)	55.0 (24)	52.1 (24)	49.3 (23)	67.0 (23)	49.8 (23)	49.6 (23)				
> 9.0	61.3 (19)	75.6 (20)	55.4 (20)	28.9 (19)	57.9 (19)	77.6 (20)	51.5 (20)	49.7 (20)				
HbA1c												
<0.070	64.8 (33)	65.7 (31)	49.9 (31)	37.9 (33)	49.5 (31)	67.1 (31)	47.2 (31)	54.1 (31)				
0.070-0.089	65.3 (18)	73.2 (21)	54.3 (20)	34.2 (19)	57.9 (19)	77.3 (20)	52.3 (20)	50.0 (20)				
> 0.09	86.5 (13)	76.9 (13)	69.5 (13)	69.2 (13)	66.7 (13)	67.5 (13)	56.5 (13)	55.8 (13)				
Insulin use												
No	70.0 (53)	72.2 (53)	56.9 (52)	43.1 (54)	56.4 (52)	70.0 (52)	51.3 (52)	55.0 (52)				
Yes	66.4 (11)	62.5 (12)	48.2 (12)	43.2 (11)	51.5 (11)	72.0 (12)	47.9 (12)	45.3 (12)				
Complications												
6	72.3 (37)	70.8 (36)	55.3 (35)	42.8 (38)	60.2 (36)	68.7 (36)	49.1 (36)	55.8 (36)				
7–8	64.7 (17)	69.9 (17)	53.7 (17)	47.1 (17)	43.1 (17)	68.4 (17)	52.4 (17)	51.8 (17)				
> 8	66.5 (10)	69.8 (12)	57.5 (12)	37.5 (10)	60.0 (10)	78.9 (11)	53.2 (11)	46.7 (11)				

ease (16% vs 19%), retinopathy (15% vs 14%), cerebrovascular accidents (9% vs 8%), neuropathy (9% vs 10%), peripheral vascular disease (7% vs 7%), and nephropathy (6% vs 7%). Most of these complications were assessed as being "minimal" to "moderate" in severity.²⁶

Compared with the nondiabetic survey respondents, diabetic survey respondents were older and were more likely to be Aboriginal, male, and overweight. HRQOL scores were lower for diabetics in all items studied.

Table 1 summarizes the mean scores for the eight SF-36 profile scores. Increasing duration of diabetes was associated with significant declines in "physical functioning," "role physical," and "general health" scores. Interestingly, duration of diabetes was also associated with improved "mental health" scores. Improved blood sugar control was associated with worse "physical functioning," "role physical," "bodily pain," "role emotional," and

"social functioning." Insulin use was associated with decreased "physical functioning," increased "bodily pain," poorer "general health," and poorer "social functioning" scores. A greater number of diabetes-related complications was associated with obvious declines in "general health" scores.

Table 2 summarizes the healthy/ unhealthy day data. Interestingly, longer duration of diabetes was associated with fewer reported "unhealthy mental" days, fewer "felt depressed" days, fewer "felt anxious" days, fewer "poor sleep" days, and with a greater number of "felt healthy" days. Better blood sugar control (i.e., lower HbA1c values) was not obviously associated with any of the "unhealthy" day items. Insulin use was associated with a significantly greater number of "unhealthy physical" days and "unhealthy mental" days, and with days "limited by health." The presence of diabetesrelated complications was associated with a significantly greater number of days "limited by health" and a higher number of "poor sleep" days.

The present study reveals that after controlling for age and Aboriginal status, the variables of interest (duration of diabetes, blood sugar control, insulin use, and diabetes-related complications) were all associated with health-related quality of life item scores.

Increasing duration of diabetes was associated with significant declines in "physical functioning," "role physical," and "general health" scores as well as the number of "felt healthy" days. There was an interesting inverse relationship between duration of diabetes and mental health—related quality of life items, including "felt depressed" days, "felt anxious" days, and "poor sleep" days. Our findings are somewhat consistent with those of Trief and colleagues, who found that compared with younger diabetics, elderly diabetics report better social

Number of days (number answered questions)												
	Unhealthy physical U1	Unhealthy mental U2	Limited by health U3	Limited by pain U9	Felt depressed U10	Felt anxious U11	Poor sleep U12	Felt healthy U13				
Nondiabetic	6.4 (634)	5.4 (636)	3.9 (639)	4.9 (634)	4.8 (631)	6.6 (633)	9.4 (625)	16.5 (605)				
Diabetic	10.8 (61)	7.7 (60)	7.3 (61)	10.3 (60)	6.7 (61)	9.6 (61)	12.0 (61)	15.2 (59)				
Duration in years												
< 4.0	11.2 (19)	9.6 (18)	7.2 (19)	11.3 (18)	9.5 (19)	12.4 (19)	13.6 (19)	12.0 (19)				
4.0-8.9	9.4 (23)	8.0 (22)	7.7 (22)	9.4 (22)	6.0 (23)	9.9 (23)	13.3 (23)	14.4 (21)				
> 9.0	12.2 (19)	5.8 (20)	7.0 (20)	10.3 (20)	4.6 (19)	6.3 (19)	8.7 (19)	19.2 (19)				
% HbA1c												
<0.070	11.0 (29)	8.6 (30)	8.0 (30)	12.7 (30)	7.5 (31)	11.9 (31)	12.4 (31)	12.7 (29)				
0.070-0.089	13.1 (19)	4.7 (18)	6.8 (19)	10.0 (18)	4.1 (18)	6.1 (18)	13.0 (18)	18.5 (18)				
> 0.09	7.2 (13)	10.1 (12)	6.4 (12)	4.5 (12)	8.2 (12)	8.7 (12)	9.3 (12)	16.1 (12)				
Insulin use												
No	10.0 (50)	7.3 (48)	5.8 (49)	10.0 (48)	6.6 (50)	9.6 (50)	11.7 (50)	15.0 (49)				
Yes	14.5 (11)	9.5 (12)	13.4 (12)	11.2 (12)	7.0 (11)	9.5 (11)	13.0 (11)	16.0 (10)				
Complications												
6	11.4 (34)	9.5 (33)	6.4 (34)	9.7 (33)	8.8 (33)	10.3 (33)	10.8 (33)	13.8 (32)				
7–8	5.4 (16)	5.1 (16)	7.0 (16)	11.4 (16)	4.0 (17)	7.8 (17)	11.2 (17)	14.2 (17)				
> 8	16.9 (11)	6.1 (11)	10.8 (11)	10.4 (11)	4.3 (11)	10.0 (11)	16.7 (11)	21.3 (10)				

functioning, better coping skills, less distress, and greater satisfaction with aspects of their lives related to diabetes.22 Many other studies have shown that well-being actually improves with age. 22,43,44 Whether this is because people learn to cope better as they get older, or because people that cope better live longer, remains to be determined.

Improved blood sugar control was paradoxically associated with worse "physical functioning," "role physical," "bodily pain," "role emotional," and "social functioning" scores. It was also associated with a significantly greater number of "unhealthy physical" days, days "limited by health," days "limited by pain," and significantly fewer "felt healthy" days. This is not a new finding. In fact, most studies that have looked at the subject of glycemic control in type 2 diabetes mellitus and quality of life have not been able to

demonstrate positive relationships between the two.22 Nerenz and colleagues⁵ reported that "tight" glycemic control (as measured by glycosylated hemoglobin) was associated with lower ratings on the various SF-36 dimensions. Lloyd and colleagues also reported that average blood glucose levels were inversely related to some of the isolated SF-36 domains, including "vitality." Perhaps lower HRQOL scores associated with improved blood sugar control reflect morbidity inherent in the need to keep blood sugars within normal levels in this patient population.

In the UKPDS trial, type 2 diabetics who had hypoglycemic events during the study had more mood disturbance and tension and reduced work satisfaction.18

Insulin use is associated with worse "physical functioning" scores, increased "bodily pain," poorer "general health"

scores, and poorer "social functioning" scores. Insulin use was associated with a significantly greater number of "unhealthy physical" days, "unhealthy mental" days, and days "limited by health." Jacobson and colleagues reported that patients on insulin reported the lowest levels of satisfaction.20 They also reported that only one SF-36 item distinguished patients receiving different treatments: the "general health" perception score revealed better quality of life for patients on diet treatment alone.20

Johnson and colleagues reported that use of insulin in diabetic Pima Indians was associated with statistically significant lower SF-36 scores in the "physical function," "role physical," "social functioning," and "general health."4 Woodcock summarized HRQOL survey responses of 131 type 2 diabetics and found that users of insulin had lower scores on five of the eight SF-36 dimensions: "physical

functioning," "social functioning," "physical role," "mental health," and "vitality."

Presence of diabetes-related complications was associated with a number of the HRQOL items, particularly the healthy/unhealthy days questions. Other studies have demonstrated that the presence and number of complications (e.g., neuropathy, retinopathy, peripheral vascular disease, and coronary artery disease) affects HRQOL.^{8,20}

Presumably, inability to demonstrate strong relationships between diabetes-related morbidity and many HRQOL items in our study reflects the fact that the vast majority of complications in our diabetic population were assessed as being minimal to moderate in severity. A study of diabetics with more severe complications would better clarify this issue.⁸

Conclusions

Strengths of our study include the fact that the SF-36 and BRFSS healthy/ unhealthy days survey items were correlated with chart-derived information, which ensured reliable diagnosis of diabetes. Many HRQOL studies rely on less reliable patient self-reporting of diabetes diagnosis. Limitations of our study include the relatively small sample size and the fact that not all diabetics living in the area completed the health questionnaire. However, we did review diabetic responder and nonresponder charts, so it is known how much the survey responder group differs from the overall clinic recorded prevalence—which is "not much." Reliability of the data could have been strengthened by having an independent review of a random sample of charts to assess for congruent findings between reviewers. Use of a diabetes-specific instruments may have detected significant changes in HRQOL more easily. 18,20

Our study results indicate that having diabetes mellitus is associated with lower health-related quality of life scores. Duration of diabetes, insulin use, and diabetes-related complications are all factors associated with healthrelated quality of life scores. Improved blood sugar control, as measured by HbA1c levels, was paradoxically associated with lower health-related quality of life scores. Strategies designed to diagnose diabetes early and aggressively manage blood pressure, hyperlipidemia, and albuminuria may not only prevent diabetes-related complications, but may also prevent irreversible deterioration of health-related quality of life in diabetic patients.

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Competing interests

None declared.

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