

## ORIGINAL RESEARCH

# Understanding relationships between diabetes mellitus and health-related quality of life in a rural community

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*Submitted: 21 May 2005; Revised: 27 July 2005; Published: 23 August 2005*

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*Rural and Remote Health 5: 441. (Online), 2005*

Available from: <http://rrh.deakin.edu.au>

## ABSTRACT

**Introduction:** There is a lack of information on health-related quality of life (HRQOL) for Aboriginal diabetic people. Objective: To investigate HRQOL among aboriginal diabetics living in an isolated, rural Canadian community.

**Methods:** Design: Mixed methods: (1) A mailed health-related survey; and (2) a population based retrospective chart review. Study Population: People aged 17 years and older living in the Bella Coola Valley, British Columbia, Canada, and having a chart at the Bella Coola Medical Clinic as of September 2001 were asked to complete a detailed HRQOL survey during the period August to December 2001. Main outcome measures: Demographics (age, sex, ethnicity). Health-related quality of life was measured using the MOS 36-item Short Form Health Survey (SF-36), and the US Centers for Disease Control healthy day's items.

**Results:** Relatively greater percentages of diabetic people ( $n = 72$  [57%]) completed the survey than did non-diabetics ( $n = 675$  [37%]). 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 diabetic people were lower than mean scores for non-diabetics in all the quality of life questions. Aboriginal diabetics reported the worst scores on almost all of our quality of life questions.

**Conclusion:** Rural diabetics experience significant impairment in their health-related quality of life. Among rural diabetics, Aboriginals report the worst HRQOL scores. Compared with other people, Aboriginals fare worse in HRQOL, which may explain the difference.

**Key words:** Aboriginals, Canada, diabetes mellitus.



## Introduction

Diabetes mellitus is an important cause of death, illness and disability across Canada, North America, and the world. It affects approximately 4.8% of Canadian adults – 20 years of age and older - which equates to over a million Canadians<sup>1,2</sup>. By 2010 it is estimated that 250 million people worldwide will suffer from diabetes<sup>3</sup>.

Having diabetes substantially increases one's risk of developing blindness, end stage renal disease, lower limb amputations, and dying from coronary artery disease, cerebrovascular disease, or peripheral vascular disease<sup>2,3,4</sup>. Type 2 diabetes is of particular concern to Aboriginal people because of higher prevalence rates, early age of onset, and - in many tribes – more serious course<sup>5,6</sup>. Type 2 diabetes has gone from being nearly nonexistent in the North American native Indian population in 1940 to current epidemic proportions<sup>5,11</sup>. According to a report published by Health Canada (2000), the prevalence rate of diabetes among the First Nations people in Canada is two to three times that of the general population of Canada<sup>5,6</sup>.

Although it is well documented that diabetes is strongly associated with morbidity and mortality, less is known about how this disease affects functional health status and sense of wellbeing. Health-related quality of life (HRQOL) is a subjective term which basically refers to perceived discrepancies between one's expectations and one's actual physical, emotional, and social functioning. As one might predict, people with diabetes rate their HRQOL significantly less favorably, on average, than people without diabetes<sup>12-15</sup>. A literature review on the broad topic of health-related quality of life among Aboriginal diabetics found no Canadian publications, and only a few American publications<sup>14,16</sup>. One of the American publications was a study by Johnson et al., entitled *Health-related quality of life of Diabetic Pima Indians*<sup>14</sup>. HRQOL was assessed in 54 diabetic Pima Indians living in southern Arizona using the SF-36 Health Survey. SF-36 scores for these 54 Pima Indian diabetics were lower than

those published elsewhere for non-Aboriginal diabetic population groups. The Pima Indian study design did not allow for investigation of the relative impacts of such things as gender, race, age, weight – all risk factors for developing diabetes – on health-related quality of life scores.

The Bella Coola Valley is an isolated rural community located in the central coast region of British Columbia<sup>17</sup>. According to the 2001 Census 2285 people live in the Bella Coola Valley, with 46% of these people estimated to be of Aboriginal descent<sup>18,19</sup>. Bella Coola Valley is part of the traditional territory of the Nuxalk Nation, a tribe of Salish-speaking Coastal Indians<sup>20-23</sup>. Age-adjusted prevalence rates for Type 2 diabetes in this Aboriginal population is more than two and half times that of the non-aboriginal population (12.5% vs 4.8%)<sup>24</sup>. One-third of Nuxalk Indians 65 years and older have diabetes. Age, weight, aboriginal status, but not sex, are all associated with having diabetes in this population. The development of diabetes in both Aboriginal and non-Aboriginal people living in the Bella Coola Valley is clearly associated with the presence of multiple co-morbidities including hypertension, hypercholesterolemia, coronary artery disease, cerebrovascular disease, and neuropathy<sup>25</sup>. Rates of diabetes associated co-morbidities were similar for both Aboriginal and non-Aboriginal diabetic populations.

The specific objective of this present study was to investigate HRQOL in diabetics living in Bella Coola Valley. We were particularly interested in finding out whether or not significant differences between diabetics and non-diabetics remained after taking into account the relative impacts of age and ethnicity (Aboriginal vs non-Aboriginal).

## Methods

### *Community participation*

This research project has been carried out in a participatory fashion, following the recommendations outlined in a



recently published policy statement entitled *A Guide for Health Professionals Working with Aboriginal Peoples*<sup>26-28</sup>. A goal of these recommendations is to make the relationship between Aboriginal people and non-Aboriginal healthcare providers a fair and honorable one.

There was consultation with the Nuxalk Band Council, community members and local healthcare providers on our plans to study determinants of health and disease of people living in the Bella Coola Valley. Dr Thommasen participated in potlatches (ceremonial meetings) asking for community support and explained the types of health projects we were planning to do. Prior to collecting data we obtained letters of support from the Nuxalk Band Council, from the Bella Coola Transitional Health Authority, and from Central Coast Regional District. Ethics approval to collect data was obtained from Research Ethics Committee's located at both the University of British Columbia, and at the University of Northern British Columbia. The results and the manuscript were reviewed and approved for publication by both Nuxalk Health professionals and by United Church Health Services health professionals.

### **Chart review details**

Two retrospective reviews of clinic charts were conducted by HT. The first chart review was done in July-August 2001 to determine an 'active' September 2001 clinic population. Names and addresses were tabulated onto an electronic spreadsheet and these were used for the mail-out HRQOL survey which was happening simultaneously.

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, 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 Band lists, a locally available genealogy, clinic chart, and from the survey<sup>29,30,31,32</sup>. The diagnosis of diabetes was based on the

1998 clinical practice guidelines for the management of diabetes in Canada<sup>2,33</sup>.

### **Health and health care survey**

A Health and Health Care Survey was offered to all adults living in the Bella Coola Valley between August 2001 and May 2002<sup>30</sup>. 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 given to each questionnaire sent out. 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 completion of a questionnaire.

The precise questions from the survey which were used in this study are shown in Appendix I. The first 36 questions consisted of the 36-item Medical Outcomes Study Short Form (SF-36) questions<sup>34-37</sup>. The 36-item Medical Outcome Study Health Survey 36-Item Short Form (SF-36) is one of the most frequently used and 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 for other developed countries. The SF-36 scale works best as a health profile measure with eight dimensions, rather than as a single summative measure. The eight different health dimensions/health concepts evaluate an individual's:

1. physical functioning [PF] (10 items)
2. social functioning [SF] (2 items)
3. bodily pain [BP] (2 items)
4. role limitations caused by physical health problems – role-physical [RP] (4 items)



5. role limitations caused by emotional problems – role-emotional (RE) (3 items)
6. emotional well-being – Mental Health [MH] (5 items)
7. energy/fatigue – Vitality [VT] (4 items)
8. general health [GH] perceptions (5 items).

In addition, it has a single item addressing perceived change in health status over the preceding year – health transition. The SF-36 scale scores range from 0 to 100, with higher scores indicating better functioning, wellbeing, and state of health. Reliability and validity of the SF-36 have been demonstrated for both insulin-dependent diabetes mellitus and NIDDM patients<sup>2,35,38,39,40</sup>.

Besides the SF-36 questions, there were items from the United States Centers for Disease Control and Prevention, Behavioral Risk Factor Surveillance System (BRFSS) pertaining to number of unhealthy days and special limitations/problems<sup>16</sup>. Eight items from the BRFSS were used in this study (Appendix I).

### *Statistical analysis*

Chart and survey-derived information was entered into an electronic spreadsheet (EXCEL), with names and addresses removed. Results were summarized using EXCEL. Formal data analysis was done with SPSS Windows software (SPSS Inc., Chicago, IL, USA). In all tests, a 0.05 level of significance was used.

Domain scores for the SF-36 instrument were computed following the protocol of Ware and associates<sup>34</sup>. Demographic characteristics - age, gender, and ethnicity - were used to assess response rates by comparing diabetic and non-diabetic respondents to the whole Bella Coola Valley population.

One-way analysis of variance was used to compare the four study groups (diabetic/non-Aboriginal, diabetic/Aboriginal, non-diabetic/non-Aboriginal, non-diabetic/Aboriginal) with

respect to each of the SF-36 domains and each of the unhealthy day's outcomes.

Two-way analysis of covariance was then used to assess the effect of diabetes and Aboriginal status, while controlling for age<sup>41</sup>.

$\chi^2$  statistical analyses was used to determine whether more Aboriginal diabetics report their health is worse now compared with one year ago.

## Results

After excluding clinic charts of people no longer living within the Bella Coola Valley and not currently living in the Bella Coola Valley, 2329 patients made up the September 2001 clinic population list – approximately 104% of the May 2001 census estimate<sup>18,19</sup>. An estimated 47% of the September 2001 clinic population was of Aboriginal descent which is also similar to the 2001 census estimate (46%) for the Bella Coola Valley<sup>18,19</sup>. Of the 2329 clinic population 1771 were adults ( $\geq 17$  years old), and 127 of these people had diabetes mellitus. Of the 127 people with diabetes mellitus, 126 diabetics were classified as having Type 2 diabetes mellitus. There was only one Type 1 diabetic living in the Bella Coola Valley at the time of the chart review and that person did not complete a survey.

A total of 675 useable Health and Health Care surveys were returned. Of these, 72 were from people with Type 2 diabetes mellitus. Survey respondents did not answer all questions, so number of responses varies from survey question to survey question. An estimated 1771 Bella Coola adult residents were eligible to complete this survey. So the estimated overall response to the survey was 38% (675/1771), and the diabetic response rate was 57% (72/127).

With respect to the non-diabetic survey responder population, comparisons to the known non-diabetic adult



Bella Coola Valley population reveals that relatively fewer non-diabetic Aboriginal people completed the survey (34% vs 41%:  $p = 0.005$ ) and relatively more non-diabetic women completed the survey (58% vs 49%:  $p < 0.001$ ). The average age of non-diabetic survey responders was older (47.5 vs 42.6 years:  $p < 0.001$ ) than the known non-diabetic adult Bella Coola Valley population.

With respect to the diabetic survey responder population, comparisons to the known diabetic Bella Coola Valley population reveals no significant differences with respect to proportion of Aboriginal people completing the survey (61% vs 55%:  $p = 0.41$ ), proportion of women completing the survey (51% vs 46%:  $p = 0.44$ ). The average age of diabetic survey respondents was similar (60.2 vs 59.9 years:  $p = 0.87$ ) to that of the known diabetic population.

Compared with all other diabetic groups, more Aboriginal diabetics report their health is worse now than one year ago ( $p = 0.035$ ) (Table 1).

Table 2 summarizes the eight SF-36 profile scores according to diabetic and Aboriginal status. Mean scores for Aboriginal people in our study were lower than mean scores for non-Aboriginal people in all 8 health-related quality of life (SF-36) scales. Mean scores for diabetic people were lower than mean scores for non-diabetics in all 8 health-related quality of life scales. Aboriginal diabetics reported the lowest mean SF-36 scale scores for five of the eight subscales and second lowest means scores for the other three.

One-way Analysis of Variance reveals the differences between the four diabetic subgroups are all statistically significant. The  $p$  values were  $< 0.001$  for all scales except for bodily pain ( $p \leq 0.003$ ) and vitality ( $p \leq 0.016$ ).

Age is a significant covariate for physical functioning, role physical, body pain, general health, mental health, health transition but not for vitality, social functioning or role emotional (Table 3).

Two-way Analysis of Variance with age as the covariate with Aboriginal status and diabetic status as the two main factors reveals Aboriginal status has a significant main effect on general health and physical functioning (because of an interaction effect) (Table 3). The main effect of diabetes is strongly significant for role physical, role emotion, and general health; weakly significant for body pain, vitality, social functioning, and physical functioning (because of interaction effect). Only for mental health is there no evidence of a diabetic effect. The interaction of aboriginal and diabetes status is significant for physical functioning only which means that, for the most part, any difference between diabetics and non-diabetics is present for both Aboriginals and for non-Aboriginals, and the difference is approximately of the same magnitude.

Table 4 summarizes the unhealthy days for the Bella Coola Valley. Compared with non-Aboriginal people, the average number of unhealthy days for Aboriginal people was higher in all 7 health-related domains – physical, mental, pain, depressed, anxious, health restricted, sleep. Aboriginal people also reported lower mean number of feeling healthy days in the past month. Similarly, mean number of unhealthy days for diabetics were greater than mean scores for non-diabetics in all health-related domains. Aboriginal diabetics reported the highest mean number of unhealthy/limitation days, and reported the lowest mean number of healthy days in the past month.

One-way Analysis of Variance reveals the differences between the four diabetic subgroups are statistically significant ( $p \leq 0.05$ ) for all unhealthy day questions except for poor sleep and felt healthy questions.

Age is a significant covariate ( $p < 0.05$ ) for number of unhealthy physical days (U1), number of days limited by pain (U9), and number of poor sleep days (U12) (Table 5).



**Table 1: Health now compared with one year ago**

Value label	Diabetic		Non-diabetic		BCV survey
	Aboriginal n (%)	Non- Aboriginal n (%)	Non- Aboriginal n (%)	Aboriginal n (%)	Respondents n (%)
1. Much better	5(11)	2(7)	28(7)	30(14.5)	65(10)
2. Somewhat better	5(11)	4(14)	53(14)	25(12)	87(13)
3. About the same	21(48)	17(61)	264(67.5)	118(57)	420(63)
4. Somewhat worse	11(25)	4(14)	40(10)	30(14.5)	85(13)
5. Much worse	2(4.5)	1(4)	6(1.5)	4(2)	13(2)
Total	44	28	391	207	670

BCV, Bella Coola Valley

**Table 2: SF-36 HRQOL scores for Bella Coola Valley**

Mean SF-36 scores (%)	PF	RP	BP	GH	VT	SF	RE	MH
Total population	80.3	68.3	65.5	66.9	55.3	78.1	76.0	72.9
<b>Aboriginal status</b>								
Non-aboriginal	83.7	70.4	67.2	72.3	57.7	80.9	78.5	75.7
Aboriginal	78.3	63.3	62.3	60.1	53.8	74.3	70.5	69.8
<b>Diabetic status</b>								
No diabetes	83.1	70.5	66.4	69.5	57.0	79.2	77.6	73.9
Diabetes	70.1	43.9	56.2	52.5	49.8	71.4	57.4	70.8
<b>Diabetic subgroups</b>								
Non-diabetic (others)	83.4	73.1	68.2	72.4	57.3	81.3	80.2	75.2
Non-diabetic (Aboriginal)	78.1	67.4	63.2	61.3	53.6	74.6	74.4	69.5
Diabetic (other)	66.1	43.5	54.1	54.8	49.4	72.7	66.7	75.0
Diabetic (Aboriginal)	71.2	44.1	58.3	51.0	49.1	69.2	51.6	67.3

BP, bodily pain; GH, general health; MH, mental health; PF, physical functioning; RE, role-emotional; RP, role-physical; SF, social functioning; VT, vitality.

**Table 3: Two-way Analysis of Variance for SF-36 scale scores**

Status		PF	RP	BP	GH	VT	SF	RE	MH
Age	<i>p</i> value	< 0.001	< 0.001	<0.001	<0.001	0.2	0.76	0.5	0.03
Aboriginal	<i>p</i> value	0.21	0.25	0.65	0.002	0.4	0.12	0.03	0.01
Diabetic	<i>p</i> value	0.39	0.001	0.07	<0.001	0.07	0.05	0.001	0.29
Aboriginal diabetic	<i>p</i> value	0.01	0.3	0.1	0.1	0.5	0.06	0.4	0.6
<b>F-stat</b>									
Age	F-stat	154.9	46.45	13.4	18	1.5	0.1	0.5	4.9
Aboriginal	F-stat	1.6	1.3	0.2	9.6	0.7	2.4	4.8	6.25
Diabetic	F-stat	0.75	10.7	3.2	14.1	3.4	3.8	11.5	1.1
Aboriginal diabetic	F-stat	6.2	0.9	2.45	2.5	0.4	0.25	0.85	0.3

BP, bodily pain; GH, general health; MH, mental health; PF, physical functioning; RE, role-emotional; RP, role-physical; SF, social functioning; VT, vitality.



**Table 4: Unhealthy days data for Bella Coola Valley**

Status	Unhealthy physical	Unhealthy mental	Restricted by health	Limited by pain	Felt depressed	Felt anxious	Poor sleep	Felt healthy
Abbreviation	U1	U2	U3	U9	U10	U11	U12	U13
Total population	6.4	5.4	3.9	4.9	4.8	6.6	9.4	16.5
Aboriginal								
Non-Aboriginal	5.6	4.7	3.1	3.9	4.2	5.9	8.9	17.0
Aboriginal	7.8	6.5	5.4	6.6	5.9	7.6	10.2	15.6
Diabetic								
No diabetes	6.0	5.1	3.6	4.4	4.7	6.3	9.1	16.6
Diabetes	10.5	7.4	6.9	9.7	6.3	9.0	11.8	15.2
Diabetic subgroups								
Non-diabetic (others)	5.3	4.6	2.9	3.7	4.2	5.8	8.7	17.0
Non-diabetic (Aboriginal)	7.2	6.2	5.0	5.8	5.6	7.2	9.8	16.0
Diabetic (others)	10.1	5.8	5.7	7.8	4.8	7.6	10.9	17.3
Diabetic (Aboriginal)	10.7	8.4	7.7	11.0	7.3	10.1	12.4	13.8

**Table 5: Two-way Analysis of Variance for unhealthy days data**

Status		Unhealthy physical	Unhealthy mental	Restricted by health	Limited by pain	Felt depressed	Felt anxious	Poor sleep	Felt healthy
Abbreviation		U1	U2	U3	U9	U10	U11	U12	U13
Age	<i>p</i> value	<0.001	0.086	0.059	< 0.001	0.15	0.24	0.001	0.58
Aboriginal	<i>p</i> value	0.17	0.091	0.033	0.006	0.085	0.16	0.54	0.12
Diabetic	<i>p</i> value	0.052	0.048	0.041	0.006	0.14	0.033	0.009	0.68
Aboriginal diabetic	<i>p</i> value	0.41	0.58	0.85	0.86	0.54	0.60	0.71	0.43
<hr/>									
Age	F-stat	19.87	2.96	3.57	22.72	2.10	1.37	11.38	0.31
Aboriginal	F-stat	1.91	2.87	4.55	7.63	2.98	2.03	0.38	2.41
Diabetic	F-stat	3.78	3.94	4.19	7.54	2.19	4.54	6.90	0.17
Aboriginal diabetic	F-stat	0.67	0.31	0.04	0.03	0.38	0.28	0.14	0.61

Two-way Analysis of Variance with age as the covariate with Aboriginal status and diabetic status as the two main factors reveals the interaction of aboriginal and diabetes status is not statistically significant for any of the unhealthy/limitation days which means that any difference between diabetics and non-diabetics is present for both Aboriginals and for non-

Aboriginals, and the difference is about the same magnitude. Having diabetes is associated with significant negative impacts on all variables except for the number of days feeling depressed, and number of days feeling healthy in past month. Aboriginal status is associated with significant negative



impacts on only two variables: namely, number of days restricted by health and the number of days limited by pain.

## Discussion

Health care providers should strive to understand the physical, emotional, and social impacts chronic disease and its treatments have on patients/clients. Such patient-centered knowledge can be incorporated into chronic disease treatment strategies designed to improve or enhance function in every day life and improve or enhance health-related quality of life. Improved health-related quality of life may also lead to fewer office visits and hospitalizations and hence reduce healthcare costs<sup>12,16</sup>.

With respect to diabetes, this means that healthcare professionals should not just focus on objective vital signs (eg blood pressure), physical examination findings (eg retinopathy, nephropathy, heart disease), and laboratory tests (eg hemoglobin A1c values). Rather, healthcare professionals should strive to also understand the subjective impact diabetes and its management has on a diabetic's physical and mental functioning – that is, their health-related quality of life. Ideally, treatment of diabetic patients should result in both improved glycemic control and better health-related quality of life<sup>42</sup>.

HRQOL was assessed in this study using both Medical Outcomes Study Short Form 36-item health survey (SF-36)<sup>34-36</sup>, and Centers of Disease Control and Prevention (CDC) Unhealthy Day questions<sup>16</sup>. Both are well established with good reliability, brevity, validity, responsiveness, and comparability. Both were designed to evaluate aspects of functional status and subjective wellbeing.

Within the Bella Coola Valley population, increasing age, Aboriginal status, and having diabetes were all found to be associated with poorer self-reported health-related quality of life scores. Although other studies have demonstrated increasing age<sup>13,14,16</sup>, Aboriginal status<sup>14,16,29,30</sup>, and diabetes<sup>13,14,16,35,38-40,43,44</sup> are associated with poorer self-

reported health-related quality of life scores, it does not appear that anyone has studied all three variables within one single population.

Mean scores for Aboriginal people in our study were lower than mean scores for non-Aboriginal people in all 8 health-related quality of life (SF-36) scales. Compared with non-Aboriginal people, Aboriginal people also had more unhealthy days. The precise reasons for lower scores in the Aboriginal population compared with the non-Aboriginal population remains to be determined. Presumably it reflects the fact Aboriginal peoples tend to have a poorer combination of health determinants. Compared with non-Aboriginal people, Aboriginal people – including those living in the Bella Coola Valley:

1. have a higher smoking rate<sup>5,6,25,29,45-47</sup>
2. have less formal education<sup>6,29,48</sup>
3. are more likely to be unemployed – have high rates of unemployment<sup>29,48</sup>
4. earn lower incomes than others – have high rates of poverty<sup>6,29,30,38,48</sup>
5. have higher rates of illness/comorbidity (eg diabetes, hypertension, heart problems, cancer, arthritis/rheumatism, trauma)<sup>5,6,11,12,25,26,29,49-53</sup>
6. suffer from high rates of post-traumatic stress/residential school syndrome<sup>6,29,54</sup>
7. have higher age-adjusted mortality rates and lower life expectancy at birth<sup>6,29,55</sup>.

All these factors are associated with poorer self-rated health<sup>6,30,56</sup>, poorer community/population health<sup>6,29</sup>, and lower health-related quality of life scores<sup>6,30,56-59</sup> compared with communities/populations with lower prevalence of these indicators. The interaction among all these variables is complex and not easy to sort out<sup>30,16,56,57</sup>. For example, higher education is associated with higher income, greater job security, better housing, better sense of control over one's life circumstances, which presumably explains the better health and higher overall quality of life scores.



Our data also reveal that even after controlling for age and ethnicity, diabetes mellitus significantly impacts one's day to day functioning and one's self-rated health perception. In general, health-related quality of life scores reported for Bella Coola diabetics are comparable with those reported for other diabetic populations, and they are much lower than those reported for other non-diabetic populations<sup>12,14,16,43,60-63</sup>.

The reason for lower health-related quality of life scores for diabetics is probably multifactorial. Compared with non-diabetic people, diabetic people - including those living in Bella Coola Valley:

1. tend to be overweight<sup>6,16,25,64-69</sup>
2. are more likely to be sedentary and less likely to exercise<sup>30,16,61,70</sup>
3. are much more likely to have co-morbidities (eg hypertension, coronary artery disease, hypercholesterolemia)<sup>3,5,6,9-12,16,29,40,59,61,71-76</sup> and suffer from complications such as painful polyneuropathy, upper gastrointestinal symptoms (eg pain, dyspepsia, reflux, diarrhea, constipation, incontinence), impotence, retinopathy, nephropathy, and amputations<sup>3,13,14,40,44,61,63,71,74-81</sup>
4. are more likely to suffer from morbidity associated with high (hyperglycemia) and low (hypoglycemia)<sup>42,61,71,82</sup>.

All these things have been shown to negatively affect HRQOL.

Lower HRQOL scores may also reflect the fact that diabetes is a complicated disease to manage because there is no cure, and so optimal management involves asking patients to make numerous lifestyle changes of life-long duration<sup>14,39,42,60,83,84</sup>. People with diabetes are asked to follow prescribed diets, exercise regularly, stop smoking, take medications, monitor glucose levels regularly, be on the look out for complications, and some are asked to administer their own insulin. One study showed that higher quality of life was associated with greater perceived ease of adherence to treatment regimen.

Unfortunately, few diabetics are able to comply with all the lifestyle changes asked of them<sup>85</sup>.

Finally, lower HRQOL scores in some diabetics may reflect poor coping strategies and/or negative emotional outcomes. Previous research has shown that depression and anxiety negatively impact patient reported quality of life. While some diabetics cope well with their chronic disease, others adopt less effective coping strategies which manifest as anxiety, withdrawal, depression, self-blaming, blaming others, denial, aggression, shame, hopelessness, and even anger<sup>86</sup>. Depression, for example, is said to be two- to four-fold more common in individuals with diabetes compared with the general population<sup>44</sup>, with prevalence rates as high as 31.7% being reported<sup>38,87</sup>. Diabetics with a diagnosis of depression score significant lower on every dimension of the Short Form Health-Related Quality-of-Life Questionnaire (SF-36) compared with those diabetics who are not depressed<sup>87</sup>. Apparently low health-related quality of life scores in diabetics is not due to a 'labeling' phenomena<sup>73,88</sup>. Labeling refers to the negative impact of being diagnosed with a chronic illness (eg hypertension and abdominal aortic aneurysm) can have on one's perception of wellbeing.

The strengths of this study include the fact that SF-36 items and Healthy days items were correlated with a chronic disease – diabetes - which was confirmed by clinical chart review to ensure that the 'gold standards' for diagnosing diabetes were met. The study does, however, suffer from some limitations. The sample size of Aboriginal diabetics and non-Aboriginal diabetics is relatively small. Not everyone living in the valley completed the health questionnaire. However we did review diabetic responder and non-responder charts, so it is known how much the survey responder group differs from the overall clinic recorded prevalence – which was not much. Our data suffer from limitations inherent in collecting medical chart information – especially incomplete information and non-standardized measurements. 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. Notwithstanding these limitations, the main



objective of this study, to understand the relationship between diabetes and various self-reported health measurements for an isolated rural population, was still achieved.

A worthwhile study would be to compare clinic chart information (eg duration of diabetes, glycosylated hemoglobin (HgA1c)<sup>60</sup> levels, co-morbidity number<sup>13</sup> and insulin usage<sup>13,60</sup>) to see whether or not there are any correlations between chart specific information and HRQOL data<sup>86</sup>.

## Conclusion

Over the past 20 years, an epidemic of Type 2 diabetes mellitus has quietly developed among people living in the rural, remote community of Bella Coola. Our study revealed that diabetics report significant impairment in health-related quality of life compared with people who do not have diabetes. Aboriginal people report significant impairment in HRQOL compared with non-Aboriginal people. Aboriginal diabetics report the worst health-related quality of life scores.

## Acknowledgements

The authors wish to acknowledge the staff at the Bella Coola Medical Clinic for survey assistance. Dr Thommasen would like to acknowledge the Community-Based Clinician-Investigator Program for financial support.

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## Appendix I

### HEALTH and QUALITY OF LIFE SURVEY QUESTIONS

#### GENERAL HEALTH

SF1. How would you rate your health, in general, now? *(Please circle your response)*

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

SF2. Compared to one year ago, how would you rate your health in general now? *(Please circle your response)*

1. Much better now than one year ago
2. Somewhat better now than one year ago
3. About the same
4. Somewhat worse now than one year ago
5. Much worse now than one year ago

SF3. The following question lists activities you might do during a typical day. **Does your health limit you** in these activities? If so, how much? *(Please put a check (☐) in the appropriate column) For mean calculations, 1="No, not limited at all" and 3="Yes, limited a lot".*

		Yes, limited a lot (3)	Yes, limited a little (2)	No, not limited at all (1)
a)	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports			
b)	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf			
c)	Lifting or carrying groceries			
d)	Climbing several flights of stairs			
e)	Climbing one flight of stairs			
f)	Bending, kneeling or stooping			
g)	Walking more than 1.6 kms (1 mile)			
h)	Walking several blocks			
i)	Walking one block			
j)	Bathing or dressing yourself			



SF4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?** (Please put a check () in the appropriate column)

		Yes (1)	No (2)
a)	Cut down on the <i>amount of time</i> you spent on work or other activities		
b)	<i>Accomplished less</i> than you would like		
c)	Were limited in the <i>kind</i> of work or other activities		
d)	Had <i>difficulty</i> performing the work or other activities (e.g., It took extra effort)		

SF5. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (Please put a check () in the appropriate column)

		Yes (1)	No (2)
a)	Cut down the <i>amount of time</i> you spent on work or other activities		
b)	<i>Accomplished less</i> than you would like		
c)	Didn't do work or other activities as <i>carefully</i> as usual		

SF6. During the **past 4 weeks**, to what extent has your **physical health or emotional problems** interfered with your normal social activities with family, friends, neighbours or groups? (Please circle your response)

1. Not at all	2. Slightly	3. Moderately	4. Quite a bit	5. Extremely

SF7. How much **bodily pain** have you had during the **past 4 weeks**? (Please circle your response)

1. None	2. Very mild	3. Mild	4. Moderate	5. Severe	6. Very severe

SF8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including work both outside the home and housework)? (Please circle your response)

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

SF9. These questions are about how you feel and how things have been with you during the **past 4 weeks**. How much of the time during the past 4 weeks, . . . (For each question, please check () the one answer that comes closest to the way you have been feeling.) **For mean calculations, 1="All of the time" and 6="None of the time"**



		All of the time (1)	Most of the time (2)	A good bit of the time (3)	Some of the time (4)	A little of the time (5)	None of the time (6)
a)	Did you feel full of pep?						
b)	Have you been a very nervous person?						
c)	Have you felt so down in the dumps that nothing could cheer you up?						
d)	Have you felt calm and peaceful?						
e)	Did you have a lot of energy?						
f)	Have you felt downhearted and blue?						
g)	Did you feel worn out?						
h)	Have you been a happy person?						
i)	Did you feel tired?						

SF10. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)? *(Please circle your response)*

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

SF11. How true or false is each of the following statements for you? (Please put a check (☐) in the appropriate column) *For mean calculations, 1="Definitely true" and 5="Definitely false"*

		Definitely True (1)	Mostly True (2)	Don't Know (3)	Mostly False (4)	Definitely False (5)
a)	I seem to get sick a little easier than other people.					
b)	I am as healthy as anybody I know.					
c)	I expect my health to get worse.					
d)	My health is excellent.					

## Unhealthy Days and Special Problems

U1. Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health **not** good?

U2. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

U3. During the past 30 days for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

U9. During the past 30 days, for about how many days did pain make it hard for you to do your usual activities, such as self-care, work or recreation?



U10. During the past 30 days, for about how many days have you felt sad, blue or depressed?

U11. During the past 30 days, for about how many days have you felt worried, tense or anxious?

U12. During the past 30 days, for about how many days have you felt you did not get enough rest or sleep?

U13. During the past 30 days, for about how many days have you felt very healthy and full of energy?

## DESCRIPTION OF SAMPLE

The following questions are used to generally describe the sample of people who have taken part in this survey and for statistical purposes.

D1. Are you: Female (1) Male (2)

D3. Your present age:

D6. How would you name your cultural or ethnic background? (e.g., Italian, Nuxalk, Métis, English Canadian, etc.)

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