Managing and treating risk and uncertainty for health: a case study of diabetes among First Nation’s people in Ontario, Canada

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Abstract

‘Risk’ has become a key concept for understanding health care policies that are focused on prevention. Intervention no longer depends on the presence of an illness but rather an individual’s risk of developing an illness. Through ‘risk factors’ individuals are subject to medical examination and surveillance to determine the real presence of danger, based on this abstract notion of risk. This paper explores ‘risk’ and its consequences for medical intervention by focusing on biomedical practices surrounding diabetes care among First Nations on Manitoulin Island, Ontario. The first section explores the process of diagnosing diabetes. The second section outlines the treatment regimens resulting from membership in this category. The theme linking these two processes is that both diagnosis and management of diabetes depend on inclusion into categories of ‘risk’. Practices surrounding diagnosis focus on a population described ‘at risk’ for diabetes, First Nation’s people. Similarly, practices surrounding management of diabetes focus on a population ‘at risk’ for secondary complications, referring to individuals with diabetes. As the following discussion outlines, it is through the quantitative assessment of risk that scientific uncertainty is translated into definitive therapy and the need for constant surveillance.

Keywords: Risk; Uncertainty; Diabetes; Context; Aboriginal health; Canada

Diagnosing risk

This paper sets out to explore the occurrence of non-insulin dependent diabetes mellitus (NIDDM) among First Nation’s people in terms of ‘risk’. ‘Assessments of ‘risk’ — implying a threat that is socially and culturally constructed (Johnson and Covello, 1987) — are closely connected to social processes (Baxter, Eyles & Elliott, 1999, p. 91). Specifically, perceptions of risk are linked to cultural values and beliefs and thus constructions of risk occur within social and political relations of power (Douglas & Wildavsky, 1982). This social construction is a key component in theories of a ‘risk society’ developed independently by both Beck (1992) and Giddens (1990, 1991). The notion of a ‘risk society’ connects a wide array of risks to broader social processes, such as the maintenance of security. Giddens (1991) argues that modernity has destroyed the organizing principle of security which has led people to seek protective cocoons in order to face potential threats and maintain normalcy. When events occur that seem beyond individual control, such as disease, efforts are taken to re-establish normalcy. Thus this reflexive process involves:

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each other through the uncertainties surrounding risk (Baxter et al., 1999, p. 94).

Examining disease as ‘risk’ has been described as a modern phenomenon (see Beck, 1992). In general terms, ‘risk’ refers to the probability that a particular adverse event occurs during a stated period of time (Royal Society, 1992, p. 2). This view is implicitly based on the belief that causality follows deterministic laws (Kavanagh & Broom, 1998, p. 437). Further, risk has replaced ‘danger’ for conceptualizing the adverse (Castel, 1991). As such, the adverse is treated as an inherent quality of the subject — based on a combination of abstract factors — that render a generalizable event more or less probable for that subject. The connotations of the word ‘risk’ have changed from being neutral to representing an adverse and thus negative outcome (Hayes, 1992). Through ‘risk factors’, individuals are subject to examination and surveillance to determine the real presence of danger, based on this abstract notion of risk.

The implications of risk become apparent when applied to health care policies that are focused on prevention. Intervention no longer depends on the presence of an illness but rather an individual’s risk of developing an illness. It is thus no longer necessary to manifest explicit symptoms to be diagnosed with a disease. In this sense it is enough to “construct the objective conditions of emergence of danger, so as then to deduce from them new modalities of intervention” (Castel, 1991, p. 288). This shift from dangerousness to risk effectively multiplies the possibilities for intervention with little or no consideration of the human and social costs of these interventions. The use of the diagnostic test, where screening allows a disease to be identified before symptoms appear, is an example of one such intervention (Lupton, 1995, p. 78). In this sense, the event of the test creates a sense of ‘doing something’ in the face of the potential for disorder caused by illness. ‘Knowledge’ of the disease thus emerges as the sword by which the individual will protect herself from the potential threat of disease. Nonetheless, this knowledge is often imperfect and the benefits of screening for the individual — beyond the sense of simply ‘doing something’ — are not always obvious.

This paper will therefore explore ‘risk’ and its consequences for medical intervention by focusing on biomedical practices surrounding diabetes care among First Nations on Manitoulin Island, Ontario. The first section will explore the process of diagnosing non-insulin dependent diabetes mellitus (NIDDM). The second section will explore the treatment regimens resulting from membership in this category. The theme tying these two processes together is that both diagnosis and management of diabetes depend on inclusion into categories of ‘risk’. Practices surrounding diagnosis focus on a population described ‘at risk’ for diabetes, referring to First Nation’s people. Similarly, practices surrounding management of diabetes focus on a population ‘at risk’ for secondary complications, referring to individuals with diabetes. As the following discussion will outline, it is through the quantitative assessment of risk that scientific uncertainty is translated into definitive therapy and the need for intervention — against which must be set a different basis for defining ‘self’ and ‘risk’ as put forward by the First Nation’s people themselves. The paper concludes by examining the implications of these definitions for health treatment and practices.

Background

The political will to recognize diabetes as a major health care issue for Aboriginal people in Canada exists at both the national and the local levels.1 At the national level, the Assembly of First Nations (AFN) has worked towards increasing awareness, research, and developing strategies to prevent diabetes (AFN, 1996–97, p. 1). These efforts have included the establishment of the National Aboriginal Diabetes Association. Additionally, Canada hosted the Third International Native Diabetes Conference in 1995. According to Kewayosh (1995, p. 6) this conference was a milestone in the lengthy struggle of First Nations to raise diabetes as a serious health issue of national and international prominence.

To examine how both diagnosis and management of diabetes depend on inclusion into categories of ‘risk’ we undertook a study focusing on the occurrence of diabetes in two Anishnaabe (also referred to as ‘Ojibway’) communities on Manitoulin Island, Ontario. This provides a rural setting where children are initially schooled on reserve and then sent to the neighbouring town for highschool. Both communities have health centres, with little space for counselling or health promotion activities. Urgent health concerns are directed to the hospital in the nearby town. Both reserves are contemporary, with Catholic and fundamentalist churches on reserve. There was, however, a growing interest in revitalizing tradition mentioned by the majority of participants.

Both health care providers and community members identified diabetes as the most significant health problem facing these communities. The rate of diabetes was highest in the community of Whitefish River, where 42 individuals out of a total population of 291 have been

1 Following Warry (1998, p. 263) the use of the term Aboriginal is capitalized in order to “indicate a unique status and unique identity.” Additionally, the term ‘Native’ is mainly used to contrast the term non-Native — referring to “members of the predominant Western culture” (Warry, 1998, p. 264).
diagnosed — a rate of approx. 15%. In Sucker Creek, 16 individuals were diagnosed as having diabetes out of a total population of 279 — a rate of approx. 6%. In contrast, the rate of NIDDM in non-Native populations is approx. 2–5% (Young, Emoke, Szathmary, Evers & Wheatley, 1990, p. 129). Among the community members interviewed, the majority identified having individuals in their family with diabetes. When asked how long diabetes has been around, almost all community members responded that it is relatively recent, specifically within the last 20 years. Community perceptions of diabetes describe it as a contemporary health issue and thus discussion of diabetes is framed as one of the socio-historical changes that these communities have gone through in the past fifty years. As Elaine\(^2\) says:

Recently there is like an outburst among the natives. It’s all over. Everybody’s getting it.

According to the literature, NIDDM has been observed among Aboriginal peoples since the 1940s. Szathmary (1994, p. 460) describes how two decades ago, the occurrence of diabetes among Aboriginal people was described as ‘epidemic’, however, a lack of uniform diagnostic criteria made it difficult to verify this claim. Within Canada, a rise in the rates of diabetes among Aboriginal peoples has become noticeable in the past 15 years (Young, 1994a,b, p. 22). Much data has been collected in the United States, where age-adjusted mortality rates indicate that the rate of diabetes is twice as high for Aboriginal people (Young et al., 1990, p. 129). Less has been published in Canada. Young et al. (1990) did indicate several trends. In particular, their study outlined the existence of significant variability in tribal and regional prevalence rates. These rates varied from 0.8% in the Northwest Territories to 8.7% in the Atlantic region (Young et al., 1990, p. 129). They also stated that diabetes prevalence is associated with latitude in Canada, and attributed this relationship to shifts in lifestyle occurring along geographic gradients. In other words, the rate of acculturation and proximity to non-Native population influence the occurrence of diabetes among First Nations in Canada (Heffernan, 1995, p. 267; Szathmary, 1994, p. 460).

The onset of NIDDM is attributed to both genetic and environmental factors. Much of the literature has focused on the role of genetics in NIDDM due to variation in rates between ethnic groups (Heffernan, 1995, p. 268). Nonetheless, it has been argued that environmental factors have a more significant role to play in diabetes onset and that given the right conditions most populations are at risk (Heffernan, 1995, p. 268). Currently the most plausible explanation is that the increase in rates of NIDDM among Aboriginal people is a result of lifestyle changes since world war two, coupled with genetic susceptibility (Szathmary, 1994, p. 463).

Recently, a focus on the cultural knowledge surrounding diabetes has emerged from a recognition that existing treatment and prevention measures for diabetes have not been successful (Boston et al., 1997, p. 5) and that future solutions need to incorporate cultural understandings of diabetes. Two books, *Diabetes as a Disease of Civilization* (Joe & Young, 1995) and *Diabetes in the Canadian Native Population: Biocultural Perspectives* (Young, 1987) have chapters that deal explicitly with cultural knowledge surrounding diabetes (see Garro, 1995). Boston et al. (1997, p. 5) have also taken a cultural focus in a study of Cree understandings of diabetes, finding that Cree attribute its causation to the “white man” — specifically, that there is a relationship between the spread of diabetes and the “decline of bush life.” Underlying this particular study was the belief that any intervention for diabetes prevention had to be aimed towards Cree knowledge and experience of the disease. Similarly, Hagey (1984, p. 284) embarked on a study of metaphors surrounding diabetes in urban Canadian Aboriginals as a way to develop health care strategies that responded Aboriginal causal explanations. These studies indicate that illness is understood within a cultural milieu and that shared social and historical circumstances have contributed to Aboriginal understandings of diabetes and its concomitant ‘risks’.

**Methods**

The study used qualitative research methods, specifically the informal interview. A total of 28 interviews were conducted with community members — 15 individuals medically diagnosed with diabetes and 13 individuals without diabetes. Participants consisted of both males and females from a variety of age groups. Interviews took place at either the health centre or individual’s homes and all were done by the principal researcher (JS). Additionally, 18 health care providers were interviewed, including physicians, nurse practitioners, nurses, community health representatives, traditional healers, mental health workers and dieticians. Each step of the research process was undertaken in collaboration with the Health Director and the United Chiefs and Councils of Manitoulin Mnaamodzawin Health Board (UCCM Health Board) in order to ensure that the research goals fitted with the specific needs of these communities. This research was approved by both the McMaster University Ethics Board and UCCM Health Board. Following its completion a report was

\(^2\) All names have been changed to ensure anonymity.
submitted directly to the UCCM Health Board to facilitate health care planning surrounding diabetes care. Additionally presentations were made to both health care workers and board members to convey the findings of this study.

According to Bernard (1995, p. 209) these unstructured interviews are not informal in the sense that they are based in a 'clear plan'. Nonetheless, they are characterized by a minimum of control on the part of the researcher, allowing people to express themselves in their own terms. The role of the researcher within this format is to focus conversation on a particular topic whilst permitting the informant to define the content of the discussion (Bernard, 1995, p. 211). In this framework, induction is used to interpret or reconstruct reality in order to understand the processes through which people ascribe meaning to their lives (Elliott & Baxter, 1994, p. 137). The premise for this approach is that definitions of health and illness (and its causes) are based on these meanings.

Interviews addressed a range of themes in order to explore general perceptions. These themes included the following general categories: general health; causes of diabetes; conditions surrounding diagnosis; treatment; diabetes management; knowledge of diabetes; consequences of living with diabetes; and future recommendations for health care planning. Additionally, time was spent observing traditional diabetes education workshops and informal discussions surrounding diabetes often took place while waiting for participants at the community health centre.

Analysis of the data involved coding the transcribed interviews into relevant themes and topics. Following this process key codes were identified. Within this study, data was coded line by line — allowing the development of precise coding categories. In this sense, the study used 'inductive code development' — referring to the process whereby the code development occurs while concomitantly reading through the data (Wakefield, 1998, p. 117). A computer based qualitative research analysis program, NUD.IST (Non-Numerical Unstructured Data — Indexing, Searching, and Theorizing), was used to assist the analysis. Computer assisted data analysis has a number of advantages including: flexible data management where theory can be developed in relation to the data; increased retrieval capacity; and a flexible indexing system (Wakefield, 1998, p. 119). Within NUD.IST themes are coded and then organized into a hierarchical coding system. The use of analytic induction helps to avoid prior categorization of the data and identifies earlier categories that may not fit with the data (Eyles, 1988, p. 4). The process of progressive categorization and refinement of theory is based on the premise that the emergent findings will be consistent with the data. The two authors read through the transcripts to ensure rigour and reliability in coding and inferences.

**Diagnosis of NIDDM**

It became apparent in this study that among the individuals diagnosed with diabetes, these diagnoses were often a result of these individuals being at the doctor or at the hospital for reasons other than the traditional symptoms of diabetes (i.e. thirst, excessive urination, fatigue). Among those diagnosed with diabetes, three individuals explicitly identified having symptoms pre-diagnosis whereas a total of 10 individuals explained that they were at the doctor for other reasons and were shocked about being told that they might have diabetes. In this sense, people without symptoms are required to contemplate the reality of a disease that seems ‘hidden’ (Lupton, 1995, p. 94) defined by the ‘objective’ measurement of the blood sugar level. Thus the danger becomes translated through risk. According to Raymond:

They tested me about five years ago. I didn’t really expect that you know. When I was in the hospital for another reason they did the blood work.

When asked whether she noticed symptoms pre-diagnosis, Margaret responded:

No. I wasn’t ever thirsty. Or I didn’t run to the bathroom. I didn’t have none of those. And like I say, they might have been there, but I was busy working and didn’t have time to.

Dennis had a similar perspective:

When I had that asthma. I used to get pneumonia all the time when I had that asthma. That’s when they found out that I had sugar diabetes.

Interviewer: Did you have any symptoms or anything before that?

Dennis: No.

Gregory, from Sucker Creek, described his reaction to the diagnosis:

Yea. And the thing is when I did find out, it was just by chance too that I found out,…It was a surprise really.

Additionally, nine of the health care professionals mentioned situations where individuals were seeking health care for reasons other than diabetes. According to Beth:

I find a lot of people are diagnosed as diabetic is on like an emergency type basis. They go in maybe for something else and the doctor, through blood work, finds out, hey you’re a diabetic. Or they’ve had
something happen to them and it’s because of diabetes and they didn’t know they had it.

With specific reference to symptoms, John stated that:

Probably about a third of the diagnosis are based on symptoms, and those are based on fatigue. Compared to people with the classical symptoms of diabetes, weight gain weight loss. Two thirds are being diagnosed in routine physicals.

Thus, in the majority of cases, client experience of symptoms is not the most important dimension of diagnosis. Rather, it is the objective measurement of the blood glucose level that determines membership in the category of ‘diabetic’.

Risk is thus evaluated numerically and thus the measurement of the blood sugar level represents an explicit definition of danger. Through the presentation of a number, all other scientific uncertainties — including factors that may modify this risk — disappear.

Yet the objectivity behind diagnosis can be questioned. *Harrison’s Principles of Internal Medicine* (Wilson et al., 1991, p.1739) describes this process:

The diagnosis of symptomatic diabetes is not difficult. When a patient presents with signs and symptoms attributable to an osmotic diuresis and is found to have hyperglycemia, essentially all physicians agree that diabetes is present. There is likewise little disagreement about an asymptomatic patient with persistently elevated plasma glucose concentrations. The problem arises with the asymptomatic patient who for one reason or another is considered to be a potential diabetic but has a normal fasting glucose concentration in plasma.

In this sense, despite efforts to ensure objectivity — reflected in the blood sugar level — the path to diagnosis for certain individuals remains uncertain. Nonetheless, clinical guidelines have been established clearly defining diagnostic criteria. There has been a recent lowering of the diagnostic criteria for fasting plasma glucose (FPG) level (from >8.0 to >7.0 mmol/l) following the application of the revised American Diabetes Association criteria for the diagnosis of diabetes (see Expert Committee on the Diagnosis and Classification of Diabetes Mellitus, 1997, p. 1183). The implication of this change is that the incidence of diabetes will increase. As such, this diagnosis represents an “epidemic of

3Emke (1993, p. 60) argues that medical control of the body has been assisted by increasingly complex surveillance technology. These technologies are directed towards a quantifiable knowledge of the disease through an emphasis on accurate measurement.

The publication of the results of the Diabetes Control and Complications Trial (DCCT) provided clear evidence to show that strict glycemic control prevents the progression of diabetic retinopathy, nephropathy, and neuropathy in patients with insulin-dependent diabetes mellitus (IDDM) (DCCT, 1993, p. 977). The similarity between the microvascular complications observed for both IDDM and NIDDM has led to the prediction that the maintenance of near-normal glycemic levels in patients with NIDDM will also help prevent these complications (Clark & Vinicor, 1996, p. 86). This phenomenon, referred to as the “glucose hypothesis”, predicts that there is a correlation between abnormal glycemic levels and the occurrence of complications. Nonetheless, differences between the pathophysiology of IDDM and NIDDM coupled with a lack of evidence supporting intensive management of NIDDM has created a situation of considerable uncertainty surrounding proposed treatment guidelines. The results of the DCCT have increased debate over potential implications for the treatment of NIDDM (Clark & Vinicor, 1996, p. 81; Nathan, 1995a, p. 251). This debate acquires increased importance when considering that of the two forms of diabetes, NIDDM is far more common, accounting for 80–90% of diagnoses (Savage, 1996, p. 97).

Foremost in the debates surrounding the use of intensive treatment for NIDDM is the lack of long-term studies examining the risks and benefits of these therapies for patients with NIDDM (Turner, 1998, p. C35; Nathan, 1995a, p. 251; Clark & Vinicor, 1996, p.
The scientific uncertainty surrounding potential risks and benefits is evident in the following statement:

The doctrine of glycemic near-normalization for care of NIDDM — although remaining central to the diabetologist’s credo — is still regarded as a strongly held belief rather than knowledge-based fact. However strongly the findings of the DCCT and the growing epidemiologic data support this thesis, direct, scientifically acceptable evidence of benefit of glycemic near-normalization in NIDDM is still awaited. (Berger, Jorgens & Flatten, 1996, p. 157).

In Germany, this lack of evidence prompted a non-drug treatment strategy based on nutritional recommendations and increased physical activity (Berger et al., 1996, p. 153). Despite problems associated with motivating lifestyle changes, the authors maintain that this is the only possible strategy based on ‘sound pathophysiological grounds’ (Berger et al., 1996, p. 153). Nonetheless, a hesitancy towards ‘aggressive management’ of NIDDM remains the exception rather than the rule (see Henry & Genth, 1996, p. 175).

The uncertainty over the scientific basis for applying the glucose hypothesis to NIDDM originates from a number of observations, particularly the existence of adverse side effects. The DCCT cited increased incidence of hypoglycemia and weight gain as potentially adverse side effects of intensive insulin therapy (DCCT, 1993, p. 977). These increases are a concern for patients with NIDDM where large doses of insulin may be required to overcome insulin resistance (Henry, 1996, p. 97). Additional concerns regarding intensive treatment relate to the potential for the treatment to cause or contribute to cardiovascular disease (Turner, 1998, p. C35: Nathan, 1995a, p. 254). It has been suggested that exogenous insulin may contribute to atheroma (Stout, 1990, p. 631), and epidemiologic studies show a relation between high plasma insulin concentrations and myocardial infarctions (Després et al., 1996, p. 952). Studies in the UK have shown that 9% of patients with NIDDM develop microvascular complications within 9 years of diagnosis, whilst 20% have macrovascular complications (Turner, Cull & Holman, 1996, p. 136). Additionally, macrovascular disease accounts for 59% of the mortalities of these patients. The profound consequences of even a slight increase in cardiovascular disease in patients with NIDDM has led some researchers to suggest that the increased risk of macrovascular complications associated with intensive therapy outweigh its potential benefits (Nathan, 1995a, p. 254).

The recent publication of the United Kingdom Prospective Diabetes Study (UKPDS) sheds some light on these issues (UKPDS, 1998, p. 837). The UKPDS demonstrated that intensive glucose-control treatment substantially reduces the frequency of microvascular complications in individuals with NIDDM but has no effect on diabetes-related mortality or myocardial infarction. The study outlines weight gain and the risk of hypoglycemia as disadvantages. There was no evidence that intensive management had an adverse effect on macrovascular disease. Nonetheless, in the University Group Diabetes Program there was no evidence that improved glucose control, by any therapy, reduced the risk of cardiovascular complications (University Group Diabetes Program, 1978, p. 37). This study did, however, show an increased risk of cardiovascular mortality in patients given sulphonylurea. Although, the UKPDS study clarifies certain issues; specifically, the benefits of intensive therapy on microvascular complications; there remains significant uncertainty concerning the usefulness of intensive therapy for patients with NIDDM. The significance of macrovascular complications for NIDDM related mortality coupled with the finding that glucose control has no effect on macrovascular complications (UKPDS, 1998, p. 837), creates a level of uncertainty surrounding the aggressive management of NIDDM. Currently, the effects of glucose control on different groups of people with NIDDM, such as the elderly, remains unknown (Colwell & Clark, 1996, p. 178). Additionally, it is unknown whether there should be different goals for glucose control at different stages of the disease.

Biomedical perspectives on diabetes management

Clinical science demonstrates that the knowledge forming the rationale for management of NIDDM is uncertain. Nonetheless, this knowledge and the power it expresses surrounding diabetes management do not repress, but rather incite action. For individuals who are faced with the occurrence of diabetes and a potential loss of ‘health’ (in the form of complications) the possibility ‘not to act’ is excluded. What makes the power articulated over diabetes management acceptable is that:

It doesn’t only weigh on us as a force that says no, but it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. (Foucault, 1980, p. 119).

What remains unspecified in this discourse is that individuals are morally bound to assume responsibility for their health. In the case of diabetes, responsibility is expressed through careful management of the disease and responding to the danger inherent in possessing ‘risk factors’.

The need for the individual to assume responsibility for their illness is implicit to the clinical encounter, despite uncertainty within clinical science. DelVecchio
Good (1995, p. 188) discusses the bridge between the two worlds of clinical science and illness management in terms of ‘clinical narratives’. Within these messages:

Narrative time shifts from the immediate to the future. And although the future is uncertain, and expressed statistically so, the immediate and mundane have a measure of certainty, of recommendations that are ‘absolute’. (DelVecchio Good, 1995, p. 188).

Therefore the construction of the clinical narrative, emplotted by a series of technical acts, creates a definitive and competent therapeutic course for the patient — despite an uncertain future. One such act is the measurement of the blood sugar level. The lack of clear evidence to advocate intensive management of diabetes led Posner (1984, p. 50) to discuss the regulation of the blood sugar level as a protective ritual to ward off the threat of complications where the question ‘How is my diabetes?’ is clinically translated as ‘What is my blood sugar level?’ Among the health care providers, a variety of definitions of medical management were provided. John described medical management as the following:

Diabetes management, to me, is monitoring patients for complications and ensuring their blood sugar levels are “normal”.

In this statement, the blood sugar level has a central role in distinguishing between normal and pathological. In this sense, a ‘normal’ blood sugar level is considered a fundamental component of ‘controlling’ diabetes and its potential dangers. The need to achieve a sense of ‘control’, concretely expressed in the blood sugar level, becomes meaningful to both biomedical practitioners and patients in the context of this chronic and degenerative disease.

Expanding upon this definition for management, William added:

Diabetes management, normally, I think would mean striking up some kind of therapeutic relationship in which you try to educate people about the disease itself. Hopefully, you engage the system so that they can get information about how they can modify the disease. And then you look towards the long term complications and how you can minimize the risk of those developing. That’s what I think of when I think of diabetes management.

This statement identifies the importance of individual responsibility in management. The notion of uncertainty is ‘minimized’ through management by measurement. In this sense, numbers become a “symbol of certainty amidst the noise of scientific uncertainty” (Garvin & Eyles, 1997, p. 64). This passage also outlines the relationship between knowledge and health — where ‘education’ becomes the means to achieve a state of health. As will be discussed in the following section, the assertion that knowledge and health go hand in hand has significant ramifications when the foundation of this knowledge is imperfect. The collision of experience with this expert knowledge becomes expressed in the consequences of living with diabetes. That is, it demonstrates a gap between definitions for ‘health’ emerging from community narratives and clinical definitions.

The lack of clear evidence to demonstrate that intensive management will prevent complications does not surface in conversations surrounding ‘appropriate’ courses of action. Among the health care professionals interviewed, 11 individuals stated that they consider the medical management of diabetes successful if clients comply with recommendations. The underlying message is that good management of diabetes will decrease complications. In other words, responsible behaviour minimizes danger by responding to the identified risk factor. According to Andrea:

When it goes uncontrolled then it leads to a lot of complications.

Similarly, William stated that:

There’s a tremendous amount of fear around these complications, and the message doesn’t get out that there is a way, probably, to avoid those things (emphasis added).

The use of the word ‘probably’ in this statement identifies a degree of uncertainty regarding the effectiveness of medical management. Nonetheless, rather than focus on the uncertainties regarding the effectiveness of treatment, biomedical discourse centres on the risks associated with the lack of treatment. Karen highlighted this call to action amidst the uncertainty:

I think [complications] happen anyway in most people. I think you’re lessening the time. You don’t know if things are going to happen or if they’re not going to happen to you, but if you manage your diabetes better then maybe you’ll get more quality time out of your life, or maybe it won’t happen at all.

4 DelVecchio Good’s discussion centres on the practice of oncology and the bioscience of cancer.

5 In this study the term ‘diabetes’ was often used interchangeably with the term ‘sugar’ by members of the community. Some examples of the use of this term are: “I have the sugar disease”; “I’ve had sugar for four years”; “My sugar has been bothering me”.

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In most statements, the future course of the illness remains largely unpredictable — yet manageable. Unpredictability is a necessary consequence of translating clinical science into diabetes treatment — that is, the uneasiness that results from applying universal ‘truths’ to specific contexts. John discussed this awkward relationship when asked whether the medical management of diabetes prevents or delays complications:

That’s our understanding as far as physiology goes, but there have been no signs to prove that’s the case. I have diabetics who have poor management, whose blood sugar levels have been high for twenty years who have no complications. That sort of flies in the face of that. I also have patients who are well managed who go on to complications. So monitoring blood sugar is no guarantee.

This statement calls into question the emphasis in biomedical discourse on reducing uncertainty through the measurement of the blood sugar level. Nonetheless, within this narrative, the universal category of ‘diabetic’ remains stable despite the apparent lack of stability within its confines. To explain this lack of predictability William described the importance of individual effort in treatment:

We can tell people that their risk of complications is lower if they manage it. The problem is that they see a lot of people managing it but still going on to complications. Half, or not even half manage it. And what we’re really talking about when we’re talking about preventing complications, we’re talking about serious management. It requires a fair bit of effort (emphasis added).

Once again, the category of ‘diabetes’ and the corresponding treatment regimen are left intact, rather it is individual response to this ‘fact’ that is called into question.

Despite the certainty of the therapeutic course to be taken, health care practitioners are not offering certain predictions about the future health of the individual patient. According to John:

I put it into a whole package, managing your blood sugar, we expect will minimize your complications. But there is no guarantee. So in five or ten years when people have eye problems they’re not surprised by it (emphasis added).

But what is more certain is the need to ‘act’ and as such fulfilling the moral responsibility of a caregiver. The material and technical acts required to manage diabetes ground both the client and the health care provider in an ‘active’ pursuit of health. Nonetheless, previous descriptions of management by health care providers represent ‘ideal’ scenarios. When asked to comment on how he approaches diabetes management on a day to day basis, William responded:

What we do a lot of the time is people come in and we say “Gee, your sugar is high today”. That’s sort of the sum total of management. And that’s most unsatisfactory.

When asked to comment on their interaction with clients regarding diabetes management, Connor replied:

Especially with older First Nations patients, they’re real polite and they don’t want to cross you and they so “Oh yes, thank you very much and go away and don’t do anything”. In their interaction with you, they don’t want to make you angry. And the clinics over there, they plan around that day. “Well, I’ve got to get up early, make sure my sugar’s OK”. And they’ll sometimes actually apologize to you, “I completely forgot I was coming today, that’s why my sugar’s so high...because I wasn’t careful this morning like I usually am when I come to see you” (laughs). And that’s a real eye opener because when they’re careful and they come see you, their sugar is 20 and when they’re not careful it’s thirty. I mean that’s not everybody, but there is this idea that they need to please you, and I say that “you shouldn’t be doing it for me”.

This tension between clinical knowledge and individual behaviour will now be explored through First Nations narratives. Are individuals motivated to manage diagnosed diabetes? Answering this question will entail a discussion of the ‘self’, who is considered ‘at risk’.

First Nation’s perspectives on diabetes management

Contrary to the perceptions of biomedical practitioners, among the First Nations people interviewed the majority stated that they ‘closely’ manage their diabetes. When asked what motivates them to closely manage their diabetes, individuals mentioned both the fear of having to use needles, and also the fear of secondary

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6We are using ‘self’ to imply the individual’s repository of identity and worth as viewed by themselves and others. It serves as society in miniature for the individual and others, being our stance in and to the world (Shibutani, 1962, p. 132).
complications. This fear of having to take insulin injections was articulated by Emily:

I think the reason why I really watch myself is because I'm afraid of the needles, because I watched my parents take needles.

Annie also mentioned this fear coupled with the realization that diabetes was a chronic disease:

I thought a couple of pills and it'll go away in a week or so. [The doctor] said you'll have it for life. First comes the pills he said and then comes the needles. Well they said the magic word.

For a number of individuals there was a tolerance of biomedical interventions to a point — after which the disease itself is considered less damaging than the intervention. Dennis described what his reaction would be to having to take insulin:

I try to follow up to the best of my ability. Before I wasn't taking any pills for it. But it got out of hand and I had to settle for pills. And the next round will be the insulin. I told the doctor if it's up, if it's going to come to that, forget it, I said.

A fear of the secondary complications of diabetes was also mentioned in discussions of diabetes management. Margaret discussed these fears:

I worry about the complications, going blind. But I try not to think about them. It causes stress if you worry too much. Worrying about your blood sugar that causes stress...I didn’t want to end up with losing my feet and eyesight and all that. I figured if I followed the diet and stuff that I wouldn’t get to that point.

Within this statement, ‘action’ is intimately related to biomedical definitions that focus on health as a predominantly physical state. In contrast, when placed within Aboriginal definitions for health, stress as a side-effect of management by numbers can be considered detrimental to ‘health’.

Resonating with biomedical narratives, most of the respondents articulated the belief that close management of diabetes would prevent secondary complications or having to use needles. David discussed this perspective:

Those fears of getting beyond those limits sometimes scare me. What could happen if I go there, if I go too low or too high. But if you keep really looking after everything you shouldn’t have to have that worry.

As a corollary to this perspective is a sense of individual blame and responsibility if the disease progresses to the point where insulin injections are required or secondary complications occur. This sense of individual responsibility was evident when Doris discussed her brother:

When he got this care he did ok. Ok, I’m going to exercise, I’m going to do all this. And he did. And then after awhile, he went back to his old habits. And now he’s dependent on needles. See he could have prevented from going to the next step, but he didn’t. So you can prevent it from going to the next step. But no he went back to the old habits. I said, gosh, it kind of makes you angry. Why do you do this when you could have prevented it?

This statement highlights the moral choices underlying clinical management. In other words, diabetes management is not a morally neutral venture — rather, the concept of the blood sugar level provides a tangible marker on a path towards righteousness through control of a biomedically diagnosed risk factor. Within this statement, Doris’ brother strayed from this path and therefore is required to live with the moral weight of this decision — expressed in the form of complications. Thus, among those interviewed, there exists significant fear relating to the personal and social costs of going beyond the prescribed limits coupled with a corresponding sense of blame if one does.

Barriers to management

According to the health care providers poor compliance with lifestyle changes and a fatalistic attitude towards illness were the most important barriers to effectively treating diabetes. The underlying message in these narratives is that treatment is an individual’s responsibility and that barriers to proposed treatment are due to lack of compliance. Barriers mentioned in this study resonate with a previous study on Manitoulin Island which explored the perceptions of clients and physicians concerning diabetes care (Yeates, Houlden & Bedard, 1996, p. 9). In contrast, for many of the First Nation’s people interviewed, structural constraints and the emotional consequences of living with a chronic and debilitating illness were among the most important barriers to managing their diabetes — despite an articulated desire to manage the illness. Nonetheless, when disease is conceived within Aboriginal frameworks for health, explicit attention to the physical impact of diabetes is inadequate. In other words, omitting other dimensions of disease — specifically its social and emotional consequences — impedes treatment. Therefore, it is not the disease itself that is the barrier, but
rather explicit attention to only one component of the illness experience that represents a barrier to management. Although the desire to manage diabetes is articulated by community members, their inability to do so refocuses discussion to how ‘health’ in a holistic sense is being impeded. The following section will outline further divergences by considering the underlying concepts of the ‘self at risk’ that emerge from Aboriginal and biomedical perspectives. Simply stated, ‘danger’ is defined in relation to ‘risky’ behaviour on the part of biomedical practitioners and thus under the control of the individual. In contrast, for Aboriginal people ‘danger’ is present in the socio-political landscape and thus control of these risk factors is beyond the capacity of the individual.

**Biomedical perspectives**

Among the health care professionals, 13 individuals believed that poor compliance with lifestyle changes and denial of the disease prevented clients from effectively managing their diabetes. According to Beth:

I think they don’t really take diabetes seriously. Until it gets too unmanageable where say they’ve had a leg amputated or foot amputated. But even then, in a lot of those cases, that person still goes on smoking. And I think too when they’re elders they get more set in their ways as to what they’re going to do, and you can’t tell me to do this and all that kind of stuff. And there’s such an avoidance of having to see a doctor too around here. I don’t know. They probably explain all that to the people. But if they have it set in their mind that, I ain’t going to do a damn thing you tell me, that’s kind of what they’ll do. They don’t really put a value on what the doctor or what the diabetes clinic has told them. They’ll just go back to their own lifestyle, what they know, and what they do.

In this statement there is a sense that clients act irresponsibly by not taking their health ‘seriously’ and as such can be blamed for their illness. Despite the provision of knowledge — i.e. recommendations by experts — there is a sense that individuals ignore advice given, apparently downplaying biomedical notions of risk. This is a ‘self’ seen as consciously avoiding healthful activities despite being empowered through knowledge. By implication, this is also a ‘self’ that resists institutional authority.

Among the health care professionals, 11 individuals mentioned having difficulty communicating with their clients. According to William:

But I can tell you that in that six years, there is a cluster of people that I’ve been seeing, once a month or so. It’s always the same. There’s something about the way I’m interacting with them, something in which they see the disease culturally and I’m not able to communicate effectively my concerns about the disease, or generate interest.

John discussed what he considered to be at the root of these barriers:

There are cultural barriers, I think mainly because people don’t understand diabetes as a major health problem.

Scientific knowledge articulates that diabetes is a serious disease requiring biomedical intervention. The above quotes identify seemingly ‘different’ perceptions between health care providers and clients. In this sense, John articulates the fact of diabetes exists, and thus attention to this fact requires active management. Ignorance of this fact (i.e. the perception that clients do not view diabetes as a serious health problem) — coupled with the obligation to pursue health — identifies an individual that ignores risk and thus resists its moral obligations.

When discussing how perceptions of the disease differ between themselves and their clients, 7 of the biomedical practitioners discussed a fatalistic attitude on the part of clients as a barrier to effective management. Karen described this attitude:

I’ve been told that ‘when you get your diabetes, you’ll know what I mean’. And I thought, pardon me? And this is by maybe a 40-year-old saying when I get my diabetes. So I think it’s becoming an accepted way of life almost. And like I thought, well actually I’ve been taking care of myself quite well, I don’t expect to develop diabetes.

Contrary to the ‘self’ described by health care providers which actively pursues health, Jane discussed client attitudes towards treatment:

I think that part of the problem is that, in many of these families, other family members have had diabetes and it goes past the point of being an illness. It’s almost like a natural part of the aging process. So that the impetus for treating yourself aggressively, it’s not there.

This idea of normality was repeated in William’s statement:

Yeah, it’s almost normal when it’s in the family, like “Oh well, she’s diabetic”. Sort of an inevitability about it.
The subject who perceives ‘normality’ whilst simultaneously being in a disease state further identifies the self as aberrant from a biomedical perspective. Nonetheless, Geoffrey, a health care provider, discussed the structural and historical background of this perceived self:

Well, I think that basically a lot of the attitude in First Nations communities is fatalistic because they haven’t had control. It’s kind of been zones of oppression in that they haven’t been allowed to make decisions. Someone has told them. It goes back to the old health posters that used to be on the walls, “check with your local physician”. In First Nations you didn’t do anything without accessing a physician. Because everything was against the law, to have traditional medicines, different ceremonies. So as a result you basically taught a dependency. You took away independence and ability to treat oneself and put that all in the hands of the health care system and the physicians. And then they turn around and say, “Why is everyone running to emergency? Why are First Nations always running to the doctors office?”. Because you told them and trained them not to use anything that you couldn’t buy off the shelf. They really disabled individuals in the community.

Geoffrey’s discussion of a general lack of ‘control’ is significant for the ‘self’ that faces a disease that demands ‘control’ in the form of self-management.

In sum, within the biomedical narratives there is a sense that the pursuit of health is an individual responsibility. As such, the choice not to engage in healthful behaviours according to biomedical definitions for health identifies a self that is immoral. As will be evident in the following section, a divergent perspective of the ‘self’ emerges when health is defined within Aboriginal frameworks.

First Nation’s perspectives

The discussion to follow highlights the elements of living with diabetes that are not addressed by biomedical definitions of diabetes and diabetes management. First Nation’s identification of barriers to treatment portrays a different ‘self’ than that articulated in biomedical discourse. The subject position of this self is not deviant but is rather engaged in the complex interactions between everyday experience and structural constraints. According to Elaine:

Yea. It scared me. It scared me to control it. To really look after it.

The existence of fear surrounding both the disease itself and the ability to ‘control’ it demonstrates that individuals are concerned about management, and that the corresponding consequence of not being able to manage diabetes is significant. Thus, rather than the position of the deviant self previously discussed, the individual who is dealing with diabetes (albeit in their way) has an intimate, as opposed to objective, knowledge of these consequences. Within these narratives, the dangers of diabetes are real though not necessarily related to identified risk factors. For Dennis, who had recently recovered from cancer, being diagnosed with diabetes had this effect:

I felt like somebody had stabbed me with a big knife. Now what the hell kind of sickness is this?

Following diagnosis, a number of individuals mentioned feeling a sense of anger at being told that they had diabetes. This anger relates to a perceived loss of freedom to pursue a chosen lifestyle. Eugene mentioned his first trip to a grocery store following his diagnosis:

Yea rage. I stopped at the store on the way home from the hospital and aisle after aisle of stuff I perceived I couldn’t eat. I thought there’s nothing left for me here. But there’s lots left. You can’t see the tree for the forest. You’re looking at all those goodies with miles and miles of sugar.

David described his feelings:

I was really, I don’t know, I was angry with my doctor around for awhile. I was really mad. I said, what? He says, “you’re diabetic”. This sucks. I hate this right now. He’s just looking at me and he says, “hey calm down. I’m just telling you, I hate to bring bad news, but you’re really going to have to change your tune”...I do all this stuff, like say “ok I’ll quit drinking, become a better person”, right? And here is what my reward is — what the diabetes? Come on man, if there’s a God up there, when I get up there, I’ll kick his ass. That’s how I felt. I felt really, really angry. Disappointed. Sad. Resentful. Just a lot of different things. All negative mostly because look man what the hell, I’m doing all this, and this is how you repay me, fucker. I don’t know, I was really, really angry...I’ve been living a pretty good healthy lifestyle compared to others. It should have probably struck them more first but it didn’t, it hit me first. That’s just a fact I hate. I can’t accept it...It’s really frustrating because these guys run their bodies to shit all day long whatever, don’t eat or drink for 4, 5 weeks straight.

David conveyed a strong sense of injustice, where despite his individual efforts to change his lifestyle he is still unable to achieve his desired state of health. With the onset of a chronic illness, such as diabetes, health
becomes an unattainable goal. David described the position he now finds himself in:

Yea I'm ashamed of it. I don't want to have it. I only thought it would be someone's disease like when they're 50. To affect someone as young as me, it just sucks.

Denial as a response to being diagnosed with diabetes was also mentioned by most respondents. Raymond defined what he meant by denial:

I go a lot of days without thinking about it. I take my medication, block out that I have diabetes. Sometimes I think about it. When I go to see the doctor, that's mainly when I think about it. Sometimes if I wait to long for a meal or a snack I get the shakes, then I think about it.

When asked to characterize this denial, Annie responded:

It means I wish I never had it. Or why is it me? Then I have bad days. Then I have good days. But I try and not think about it. If I have a sore toe, I panic because I don't want my foot cut off. And I've seen so much of that. You hear so much about it. It's just what would I do, what would happen...I lose my arm or gangrene this, this, this nonsense. Not nonsense, but this should happen because it all goes back to diabetes. Everything. Everything goes back to diabetes.

Dennis described what he felt was at the root of this 'denial':

I don't know...People who have diabetes just don't care anymore because there's no way to cure them anyway.

This statement could be interpreted as a fatalistic attitude, yet it can also be interpreted as a form of grieving. In other words, it represents a response to the 'loss' of normality in one's life. The occurrence of diabetes throws 'order' into question and thus responses to diabetes, such as denial, are directed towards viewing danger in the context of everyday living.

Margaret discussed denial of the disease relating to the stringency of required lifestyle changes:

I think their diet, of what they're supposed to eat. I think that's why I denied it. I had to go on this special diet. I didn't know there was meals out there you can have that aren't as bland as years ago.

The social consequences of lifestyle changes were evident when Gregory discussed not wanting other people to know:

So if you're doing something you shouldn't be doing, people will come and tell you, hey you've got diabetes, you shouldn't be doing that. So you don't like people telling you all the time. You know what it is. You don't have to be reminded. So you just don't say anything. You keep it to yourself and hope nobody finds out.

Additionally, Gloria mentioned the need to resist being labeled 'sick':

I think there's denial around a lot of things because everybody's Indians don't get that. Indians don't get that. That we're curable for everything. That there is nothing wrong with us. This is how you are type of thing...They don't like the label I guess.

When asked to discuss difficulties associated with living with diabetes, 9 individuals mentioned economic costs. Margaret discussed her own difficulties maintaining the proper diet:

You can live with it and have a decent life. But sometimes it's hard for us in the middle of the week is our hardest part because we're both pensioners. We have no source of income to fill the gap between the end and the first of the month. So when you run out of things...I try and buy enough to last from month to month, but then something always happens...we don't always have those four things that you need to have in a meal.

In this sense, managing diabetes becomes problematic when related to everyday concerns, such as limited income. Gregory outlined these same problems:

I think for one thing is not eating properly. Not having the right foods for your system. I mean you have to have all kinds of vegetables. A lot of people can't afford these things. They just eat potatoes dipped in grease. Some people just don't have the funds. A lot of people that have jobs, they can afford stuff, but a lot of people don't. And then you don't have a job. You're living from one welfare day to the next. And that's stressful. Nobody wants to be on welfare. Everybody wants to work. But a small reserve like this, there's no work. Only certain people work and the rest of us have to sit around They have health clinics but when you go home, what are you going to eat? This is what you're supposed to eat. Well, hey listen, I've only got so much in my welfare cheque and I can't afford all this fancy stuff.
In this statement, there is a sense that the social and economic realities of life on a reserve impede personal worth that is reflected in the ability to work.

Yet some individuals explicitly mentioned that they do not feel that the lack of money is an issue. According to Sylvia:

Oh I think they can, it’s just that they don’t put out the money because they want to get this. So material. I really believe people here or any community can really afford what they want to get. But groceries, their grocery list goes down even more, and they don’t get what they should get.

Thus individual lifestyle choices remain an important dimension of diabetes management for some First Nations people.

In sum, in both biomedical and community narratives a key theme that emerges is the desire to achieve ‘normality’ in the face of illness. Nonetheless, normality and its pursuit are defined differently within these two frameworks. According to biomedical narratives normality is achieved through the measurement of the blood sugar level. The motivation to manage within this framework is based on uncertainty regarding the implications of poor management and the danger regarding the potential onset of secondary complications. In this sense, danger is inherent to certain individual behaviours. In contrast, community narratives focus on the social rather than the physical consequences of diabetes. For community members, it is the loss of freedom associated with the onset of diabetes that needs to be redressed in order for ‘normality’ to be achieved. Their inability to achieve this normality, despite knowledge of the recommended behaviour changes, identifies that danger is beyond the individuals ability to control. These divergent definitions of danger, and the inclusion of only the biomedical definitions within management, highlight the extent to which risk assessment literature fails to distinguish between socially produced and naturally occurring risks (Hayes, 1992, p. 405). Further, the negative connotations associated with the word ‘risk’ create a problem when poor management of diabetes is considered a ‘risk taking’ venture implying negative intent on the part of the actor.

Conclusions

The medical construction of diabetes has created a population “whose health is endangered in a common, though individualized way through the concept of ‘risk’” (Harding, 1997, p. 141). Therefore, all individuals located within the universal category of ‘diabetes’ are at risk for developing complications. As participants in society, individuals are given the option to pursue health as a resource for living. Nonetheless, current health promotion literature also articulates an individual’s obligation to pursue health in order to be considered a responsible member of society (Nettleton, 1997, p. 208).

The implication is that each of these individuals has not only the right but also the duty to manage diabetes and prevent future illness.

The ‘self’ to which biomedical discourse speaks is autonomous, subjective, and active and maintains the position that it is “the individual who is best able to make his/her life better” (Nettleton, 1997, p. 208). It is the practices and recommendations of experts in the health sciences that both define and create the possibility for health. In other words, experts assist in the process of understanding the self. In this context, the subject is constructed actively, yet never through processes that are autonomous or independent of culture and society (Foucault, 1990, p. 11).

The premise of this approach to the self is that through the process of self-transformation, the individual has the capacity to prevent further illness. According to Greco (1993, p. 361):

If the regulation of life-style, the modification of risky behaviour and the transformation of unhealthy attitudes prove impossible through sheer strength of will, this constitutes, at least in part, a failure of the self to take care of itself — a form of irrationality.

From the viewpoint of clinical rationality, control of the self can be equated with control of diabetes — where the ability to manage diabetes is considered a reflection of the ability of the self to be successful.

Despite the emphasis on individual risk factors with respect to policy, evidence exists that seriously challenges this perspective. The Whitehall study indicated that social class gradients in mortality remain after controlling for individual risk factors (Wilkinson, 1996, p. 53). This evidence strongly suggests that an approach based on individual risk factors is inadequate and that what is required is a response to these individual risk factors at a societal level. According to Harding (1997, p. 143):

The political significance of this conceptualization of health is that it is formulated as a series of common endpoints for groups and individuals, obscuring their sheer impossibility for some.

In any framework for health there is a need to consider the impact of cultural and societal practices in shaping and defining the backdrop against which different actors are then required to perform. In other words, healthy lifestyle practices are more or less attainable depending on the subject’s position in society.
This position is supported by studies of diabetes management where Chaturvedi et al. (1996, p. 427) discovered that there is a correlation between good glycemic control and a higher socioeconomic status. Additionally, socioeconomic differences in diabetes related complications were found, to an extent that can not be accounted for by improved glycemic control (Chaturvedi et al., 1996, p. 429). This evidence suggests that a more adequate framework for health would focus on the environment that establishes the level of exposure to ‘risk’ rather than directing resources towards new services to cope with high risk people, perceived as individuals responsible for their own fate. Such is the case in many Canadian First Nations Communities, where there is a persistent gradient in both socioeconomic status and health status when compared to non-Aboriginal Canadians (see Warry, 1998; Waldram, Herring & Young, 1995).

The certainty that medicine asserts is the need to ‘act’. Castel (1991, p. 283) discusses how in the face of unpredictability:

> It is better to act, since, even if unfounded intervention is an error, it is one that will certainly never be known to be such; whereas if one abstains from intervening and the threatened act should still materialize, the mistake is obvious and the [doctor] is exposed to blame.

Therefore a call to action reduces moral responsibility for the doctor by shifting blame to the ‘non-complier’ and obfuscates the structural conditions — specifically political, economic, historic, and societal — whereby some individuals are more able to ‘act’ than others. It is not surprising that risk reduction focuses on lifestyle, which is considered modifiable, thus obscuring factors not amenable to change at the individual level (Lupton, 1995, p. 85).

The construction of new categories of risk concomitantly creates new targets for preventive interventions (Castel, 1991, p. 289). Following membership into the universal category of ‘diabetic’, two possible subject positions are identified: an individual who is empowered through knowledge and actively managing their diabetes; or an individual who is disempowered and misinformed (choosing to either ignore advice given, or not having access to this information). Nonetheless, the medical position that perceived susceptibility to risk will necessarily motivate behaviour (Harding, 1997, p. 141) is questioned by individual response to this knowledge. This position is evident in Karen’s description of a lack of trust on the part of clients towards the advice given by biomedical practitioners:

> It’s kind of hard to explain, but when I have a patient, yes I think of their cultural background, but I do that for every individual patient. So that’s always a part of your background. But I don’t make a distinction that you’re different from me, whereas I’m different. Even things that I tell people that are written in literature, that doesn’t matter, because whatever is written isn’t as good as what like let’s say your elders might have said. Like scientific proof doesn’t seem to hold much weight.

What is often obscured in the medical literature is that the consequences of suggested actions are not necessarily neutral but have numerous human and social consequences. These consequences are evident in the level of fear surrounding insulin injections and secondary complications along with the emotional consequences of being diagnosed with diabetes. On another level, however, these consequences highlight how illness throws personal meaning into question. In other words, it leads Annie to wonder: “Why is it me?” and David to state: “I’m doing all this, and this is how you repay me?”. In order to cope with the loss of freedom that diabetes represents, when defined in a biomedical framework, individual responses are focused towards minimizing and coping with its social consequences. These responses include denial and stress. Nonetheless, in the realm of diabetes treatment it is not the above mentioned consequences but rather the consequence of poor management and thus progressing to secondary complications that is of primary concern to biomedical practitioners. Thus, it can be argued that the concept of danger becomes one of ‘risk’ with implications for freedom becoming one of exercising surveillance as a technique towards the pursuit of health.

What potential options does this ‘freedom’ provide? The choices left are perhaps limited, although extensive, in their implications. The first option is the use of ‘intensive management’ for diabetes, resulting in eventual treatment with insulin therapy, and thus represents the most ‘active’ approach. The consequences of this approach parallel with Harding’s (1997, p. 135) discussion of Hormone Replacement Therapy, where diabetes management will result in a market for consumers requiring pharmaceuticals, in addition to subjecting individuals to increased medical surveillance. The benefits of ‘intensive management’ remain uncertain and thus these potential implications are considerable. Yet the danger has been medicalized and all risks are seen as treatable — albeit with side-effects. The second option is an approach that focuses exclusively on lifestyle related risk factors, thus creating interventions at the level of daily life. Although a healthy lifestyle is, theoretically, a desirable goal, the differential ability of individual subjects to attain this goal is consequential.
References


