

Understanding the Encounter of Diabetes and Schizophrenia

by

James Morrell
BSN, University of Victoria, 2003

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

MASTER OF NURSING

in the Department of Human and Social Development

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Abstract

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People with schizophrenia are at an increased risk for type 2 diabetes and other metabolic abnormalities such as obesity and cardiovascular disease. Lifestyle choices of physical inactivity and diets high in fat and refined carbohydrates are significant contributory factors for obesity and diabetes in people living with schizophrenia, but there is a growing body of research and interest into the additive factor of psychotropic medications on weight gain and diabetes risk. The incidence of diabetes and the morbidity and mortality rates are reported to be approximately 2 to 3 times higher in the population with schizophrenia compared to the general population. This increased vulnerability for health complications is reflected in the profound challenges that are experienced in the population with schizophrenia.

My aim for this qualitative research inquiry has been to place into questioning the encounter with diabetes mellitus for people living with schizophrenia. I entered into dialogue with seven participants to explore new possibilities of understanding that emerged between the understandings that we each bring to the conversations. It was also my intent to bring into flux the assumptions of living with two interrelated chronic

conditions and to increase the understanding of that experience through a reflexive process that illuminates that which may be hidden or obscured.

I approached this inquiry mainly drawing on Gadamerian hermeneutics; the main task being the study of 'texts' that give evidence to what being human means and the analysis of how different interpretations and understandings are variable depending on their cultural and historical contexts. I expect this work to contribute to the generation of a richer understanding of these co-existing conditions and to create an opportunity and desire for ethical action in diabetes prevention and management for this high-risk population.

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Acknowledgments

My deepest acknowledgment is to my supervisor, Dr. Carol McDonald, for her expertise, inspiration and patience that she has shown throughout the journey of this project.

A very sincere acknowledgment goes to Dr. Marjorie McIntryre as co-supervisor for this project, for her support and wisdom.

Acknowledgments also go to Dr. Joan Wharf Higgins for her time, patience and support as committee member and to Dr. Patricia Mackenzie for her time and interest as external member to the committee.

Special thanks go to Leanne, Peggy, and Swatti, for their time and their openness in sharing insights into their practice with the population living with schizophrenia and diabetes. I also thank my other colleagues at the diabetes education centre where I work who have provided support along the way, for their insights and openness in our discussions that provoked my preunderstandings.

Dedication

This thesis I dedicate to John, one of the participants of this project, for his remarkable insights and courage, for trusting me with his vulnerability, and for believing in this research enough to have taken the time to share with me his understanding of his own health concerns.

I dedicate all the effort that went into the completion of my Masters in Nursing—the time and energy, and concentration required to get this done—to my family, Evelyn and Pascal, for their enduring support and for the time that they gave up of me during the undertaking of this degree.

Chapter 1: Diabetes and Schizophrenia: Emergence of Inquiry

The Encounter of Two Chronic Conditions: The Origin of the Question

The real work of our time may be defined by an ability to mediate meaning across boundaries and difference.

David G. Smith, *Meditations on Pedagogy and Culture*

I may state the question “what does it mean to be with diabetes and schizophrenia?” which then establishes my philosophical framework for this inquiry. However, I make a point here that it is not simply knowledge about this experience that I am venturing to discover, but the understanding of an experience that is shared by those living with the two conditions. I do not intend to claim that I do or will know what it is to live with a disabling thought disorder and to be diagnosed with or at risk for a progressive metabolic condition and the associated neurological and vascular ill health, especially to those who are less able or willing to either self-manage or to be managed. I do know that the associated complications of diabetes are related to variables such as blood pressure, central abdominal weight, and measures of blood glucose and lipid metabolism, and I know that these variables are affected by “lifestyle”, genetics, and perhaps other events. These things I, or anybody interested, can know. What I cannot know through this research is what it is to live the experience of those with whom I will be entering in conversation but this is not the intent of this project. I can only claim to understand *their knowing* and *my knowing*, and returning to the experience that is shared, or to the whole, I intend to create possibilities of understanding out of the engagement that will occur

between the participants and myself in conversation and through my engagement with the text that arises from this inquiry.

It is the placing of a phenomenon in view, complete with my own and the participants' preconceptions, which essentially describes the process of the knowledge generation that I seek to create. This process begins with a question, or in the case of this research, the imagination of life with the two unfortunately interdependent chronic conditions of diabetes and schizophrenia. The German word, *vorstellen*, means literally to put forward or in front: to stand before. Translated, it is, *to imagine* and it is this *putting forward* of life with schizophrenia and diabetes, a life that appears to me to be unimaginable, that has inspired my interest in this research topic. "Imagination naturally has a hermeneutical function and serves the sense for what is questionable" (Gadamer, p. 344, 1999/1976).

Understanding, as Ceci (2000) puts forth, is more about how we position ourselves as knowers in relation to different types of knowledge, rather than our focus on what is appropriate knowledge. "How we are related to what we think we know" (Ceci, p.59) speaks to the situatedness and locatedness of knowledge and knowers and is central to my research question and to the approach used in this study. The understanding generated through this research is deeply linguistic in nature and emerges through a circular but fluid process between the detailed parts and the whole of the particular concern of the encounter of schizophrenia and diabetes. The understanding will hopefully *speak* to other health care providers and researchers who encounter this research, either through the reading of this work or through presentations and future writing, to inspire

additional research or inform ethical health care practices concerning the vulnerable population living with severe mental illness.

My interest at the outset of my graduate studies originated directly from my work experience with clients and families living with chronic health challenges, or what has been recently named, *chronic disease management*. I have been particularly interested in the clients' capacity to make informed health decisions and in the role of the health care professional in facilitating the process of change. This interest has remained intact, however I have gradually come to accept that a condition such as diabetes is not effectively addressed without considering the complexities that include social, political, cultural and economic factors that shape the experience of living with this or any chronic condition.

At the time of writing this thesis, I am drawing on over ten years of nursing experience in the areas of mental health and diabetes education, through which I have accumulated knowledge, assumptions and understandings of these two chronic conditions. A central principle within my nursing experience—in mental health nursing and in diabetes education—involves a client-centred approach of aiming to improve the functional status and overall health of the people living with chronic conditions. The concept of client-centred care is not new, as the quote from Sir Farquhar Buzzard from 1933 (as cited in Billings & Stoeckle, 1999) identifies, “The most important difference between a good and indifferent clinician lies in the amount of attention paid to the story of the patient” (p.38). Foundations to client-centred care are based on the values and beliefs of respect, human dignity, individuals as experts of their own lives, individuals as able to make rational decisions, continuity and consistency of care and care giver,

timeliness, responsiveness, and universal access (McCormack, 2003; Nelligan et al., 2002). For this principle of client-centred care to become meaningful, I have needed to develop sensitivity to the multiple determinants of health and quality of life issues for people with diabetes or psychiatric disorders.

Managing the technical aspects of diabetes, or privileging the objective data, has had a certain appeal, however this “scientification of nursing”, as described by McDonald and McIntyre, (2001) “undermines the central experience of nursing: the subjective and embodied experience of care” (p. 234). Being person-centred requires the ability to form a therapeutic narrative between the professional and client that is built on mutual trust, understanding and a sharing of knowledge (McCormack). It is the principle of person-centredness, one that I have too frequently subordinated to the science of diabetes management in particular, that has inspired this research project.

The influence of language and culture is not limited to the unassailable position of modern science. In my writings and nursing practice, I use the terms *illness, health condition, and disease* interchangeably, as though there is little significance between them. There is also the virtually inescapable terminology that includes terms such as *stability, control, compliance, and adherence* that I use in reference to the self-management of diabetes or psychiatric conditions. I also perceive clients as having a poor insight into their conditions if they have demonstrated an inability or unwillingness to follow treatment recommendations. I am aware that my words may contribute to *control-over* relationships, between the clients and myself, and within the context of what I have believed to be appropriate healing and health promotion practice.

The knowledge and experience that I bring into the question—a question that does not only originate from what I had to seek out, but from my past experiences with working as a nurse with many individuals living with chronic conditions—reflects the inseparability of myself from this inquiry. Questioning indicates the existence of an unsettled issue, a matter for discussion as well as an invitation for a reply or a dialogue on similarities and differences (Bergum, 1989). In my attempt to understand chronic illness, it has been my assumption that that which is understood can be controlled, predicted, and ultimately, prevented. There has been great appeal for me in determining what Weinsheimer (cited in Jardine, 1998) terms “cognitive remedies” (p. 38) that are derived from the mathematization of significance. This is not the knowing that I pursue in this project—“to be better able to control, predict, and manipulate its future reoccurrences” (Habermas, cited in Jardine, p. 38)—although I am certain that I will not be able to completely disengage from this value of objectified knowledge as I enter into conversation with participants in the process of coming to an understanding on this subject matter.

In Heidegger’s (1962/1999) work, *Exposition of the Questioning of Being*, he puts forward, “in what is asked about there lies also that which is to be found out by the asking” (p. 275) and in doing so, the inquiry reaches its goal. In this sense, I am conscious of the limitations as well as obligations of inquiry. As Heidegger acknowledges, inquiry itself is the behaviour of a questioner, therefore there is a certain undeniable partiality to my questioning. What I seek then is not a claim of the essence of an event, as this would imply that there is a universal truth or reality that precedes an experience that one falls into a reality and may not be aware of it only until the

experience becomes “understood”. Rather, what I seek is the opportunity to question—to expose if I am able—the possibilities pertaining to an event that may inform the experience itself, and to add to the understanding of an experience that is shared within our world.

My research question has emerged from a context in which I perceive the lived experiences with schizophrenia and diabetes to be poorly understood and largely ignored by health care professionals and researchers. With this research, I hope to enter into conversations with participants to create new understandings of what it is to live with these two chronic health challenges. Although the conversations will occur with selected research participants, the interpretation will take place within the context of the social, economic and political landscapes in which I and the participants living with these two chronic conditions reside.

The Landscape of Diabetes Mellitus

Diabetes mellitus is a group of metabolic diseases characterized by hyperglycemia resulting from defective insulin action, insulin secretion or both (Canadian Diabetes Association [CDA] Clinical Practice Guidelines Expert Committee, 2003). There are two main forms of diabetes: type 1, which is marked by an absolute deficiency of insulin and affects about 10% of the population with diabetes; and type 2, which is associated with relative insulin resistance, reduced insulin secretion and increased hepatic gluconeogenesis (World Health Organization [WHO], 1999). Although insulin resistance is generally stable, as the disease progresses pancreatic beta-cell failure gradually occurs and the compensatory secretory response is lost, resulting in continual adaptation of strategies to maintain relative euglycemia. Type 2 diabetes affects the remaining 90% of

those with diabetes (WHO) and is becoming increasingly common, primarily because of increases in the prevalence of obesity and a sedentary lifestyle (Finnish Diabetes Prevention Study Group, 2001).

The prevalence of diabetes worldwide was 4% in 1995, and will rise to 5.4% in 2025. Although the prevalence is higher in countries that have been developed for some time, compared to countries with newly emerging economies, the number of people with diabetes differs dramatically, with predictions that by 2025 the number of people with diabetes will increase by 42% in developed countries compared to an increase of 170% in developing countries (King, Aubert, & Herman &, 1998). In Canada, the number of people with both diagnosed and undiagnosed diabetes is estimated to affect between 4.9% and 5.8% of the population (British Columbia Ministries Working Group on Diabetes, 2000). Population-based studies have identified prevalence rates that may be closer to 7% due to the number of undiagnosed cases (Leiter et al., 2001).

Diabetes is not evenly distributed across the population: older adults, people in lower socioeconomic brackets, and those from ethnic groups including Hispanic, Asian, South Asian, and African descent are at a significantly higher risk for diabetes. The rate of diabetes among Aboriginal people is three to five times higher than in the general population (Health Canada, 2003), and there is a 2- to 4- fold increase in diabetes in the population living with schizophrenia and bipolar disorder (Kabinoff, Toalson, Masur-Healey, McGuire, & Hay, 2003; Sernyak, Leslie, Alarcon, Losonsky, & Rosenheck, 2002).

The economic consequences related to the increasing incidence of diabetes are another area of concern that is frequently cited in literature and in government health

reports. The cost of diabetes care, including hospital, physician, renal and pharmaceutical care and services, in British Columbia for 2000 to 2001 was estimated at \$761,400,000. This figure is expected to at least double by 2010 (Shera, 2002). The per capita costs for hospital, medical, and, pharmaceuticals in 2000/2001 was \$4310 per person with diabetes compared to \$987 for persons without diabetes (British Columbia Ministry of Health Planning & Health Services, 2002). From a national perspective, the burden of diabetes due to health care costs, disability, work loss, and premature death is estimated to be up to \$9 billion annually (Health Canada, 2003).

Risk factors commonly associated with the development of type 2 diabetes are excess body weight; age (over 40 years); positive family history of diabetes; ethnic origin of First Nations, Asian, South Asian, African, and Latin American; and hypertension (Health Canada, 2003). Schizophrenia is recognized as a risk factor for diabetes in the 2003 Clinical Practice Guidelines from the CDA. With diet and lifestyle attributing to about 91% of type 2 diabetes (British Columbia Ministry of Health Planning & Health Services, 2002) primary prevention efforts are focused on the reduction of these modifiable risk factors. The emphasis on lifestyle modification is reinforced by multi-site, randomized clinical trials, such as the study by the Diabetes Prevention Project (DPP) Research Group (2002) and the Finnish Diabetes Prevention Study (2001), that find diabetes can be prevented or delayed by an average of 58% through intensive lifestyle intervention that includes 30 minutes of moderate physical activity five days per week, a diet low in fat and high in fibre, and weight loss of about 7% of total body weight.

People with pre-diabetes, a term for impaired fasting glucose or impaired glucose tolerance (CDA Clinical Practice Guidelines Expert Committee, 2003) are also at a high risk for diabetes. The incidence of diabetes is strongly related to these hyperglycemic states although there is evidence that other factors are independently associated with the development of diabetes, such as age, family history of diabetes, and most significantly, metabolic syndrome, a highly prevalent condition characterized by a distinctive constellation of abnormalities that include abdominal obesity, hypertension, dyslipidemia, and insulin resistance (American Diabetes Association and National Institute of Diabetes, Digestive and Kidney Diseases, 2002). Although people with pre-diabetes are at an increased relative risk for developing diabetes, it is important to note that all people who develop type 2 diabetes have experienced pre-diabetes, however not all people with pre-diabetes become diabetic. This is significant because of the practical and ethical considerations between targeting people who are at higher risk for developing diabetes versus targeting the population who are at minimal risk.

Despite the efforts of years of research and health promotion strategies on the positive effects of increased activity and weight loss on population health, meeting these goals has been frustratingly elusive. Canadian Community Health Survey (CCHS) data show that from 1994/95 to 2000/01, the number of obese Canadians aged 20 to 64 grew by 24% (Statistics Canada, 2002). Obesity is linked to heart disease, diabetes, hypertension, osteoarthritis, certain types of cancer, and a wide range of other illnesses. The Statistics Canada analysis found that obese Canadians are four times more likely to have diabetes, 3.3 times more likely to have high blood pressure and 56% more likely to have heart disease than those with healthy weights.

Diabetes can result in ill health or disability, and is considered the seventh leading cause of death in Canada (Statistics Canada, 2000). The long-term effects of diabetes include the progressive development of specific complications of retinopathies that lead to vision loss and possible blindness, nephropathy that may lead to kidney failure, and neuropathy with risk for foot ulcers and amputations, or features of autonomic dysfunction including gastro paresis, orthostatic hypotension, and sexual dysfunction. People with diabetes are at a two- to four-fold risk for cardiovascular disease and peripheral vascular disease, and a five-fold risk for cerebrovascular disease (Hux, Jacka, Fung, & Rothwell, 2003; WHO, 1999). Approximately 80% of people with diabetes die as a result of a myocardial infarct or cerebral vascular accident (CDA Clinical Practice Guidelines Expert Committee, 2003).

Glycemic control is essential for the prevention of the progression of diabetes-related complications. Randomized, controlled trials provide evidence that long-term complications of diabetes are reduced when blood glucose levels as near normal as possible (Diabetes Control and Complications Trial [DCCT] Research Group, 1993). In the DCCT, a 10% reduction in the average blood glucose level (A1C) for people with type 1 diabetes was associated with a 40 to 50% lower risk for retinopathy progression. The United Kingdom Prospective Diabetes Study (1998) showed that a 37% decline in the risk for microvascular complications and a 14% lower rate of myocardial infarct occurred with each incremental reduction in A1C of 1% for people with type 2 diabetes.

While oral medications may be initially effective for providing some degree of control for people with type 2 diabetes, most people will be unable to maintain recommended glycemic control (A1C <7%). Monotherapy is unlikely to maintain

adequate glycemic control for more than a few years, and most people with type 2 diabetes will require insulin as the condition progresses. In the UKPDS (1998) 53% of the participants treated with a sulfonyluria required insulin within a period of 6 years (Wright, Burden, Paisey, Cull, Holman, & the UK Prospective Diabetes Study Group, 2002). To be successful, insulin therapy requires accurate interpretation of blood glucose levels and timely and appropriate adjustments of insulin dosages. For people with impaired cognitive functioning, diabetes self-management with insulin therapy is especially challenging.

The management of diabetes pervades all aspects of one's life and those with the condition must attend to many variables related to their diabetes. Since this disease is a chronic illness with long-term effects, clients often must make lifestyle changes in order to manage their illness, and changes to medication regimes are also required as this disease progresses or as complications arise. Physical activity and cardio-respiratory fitness are associated with substantial reductions in morbidity and mortality for people with either type 1 or type 2 diabetes (CDA Clinical Practice Guidelines Expert Committee, 2003). Although health care professionals are able to provide helpful recommendations, advice and counselling, it is the person living with diabetes who must decide which strategies to put into practice. The shift in view from the provider to the patient being the most active decision-maker and problem-solver is central to productive nurse-client interactions and to current health-promotion practices (Glasgow et al., 2001), yet it is the person living with or at risk for diabetes who suffers the potential short or long-term health risks if appropriate and timely education and management practices are neglected by health care providers.

Diabetes is a “psychologically and behaviorally demanding disease; therefore, psychosocial factors are relevant to nearly all aspects of its management” (Delamater, Jacobson, Anderson, et.al, p. 1287, 2001). The ability to self-manage a chronic disease is not simply a matter of possessing the knowledge of what one should do. Rather, it reflects an ability to identify, organize, and integrate cognitive, social and behavioural skills to meet a variety of demands. Not only is there increasing evidence that good self-management is related to improved diabetes outcomes, but comprehensive reviews have demonstrated that, especially for vulnerable populations, positive patient-provider interactions and satisfaction with diabetes-related medical care are important determinants of effective self-management (Glasgow, Hiss, Anderson, et al, 2001; Mensing, Boucher, Cypress, et al., 2004; Norris, Engelgau, & Narayan, 2001).

Social and economic disparities for those living with a mental illness are also more prevalent (Reutter, 1995). Combined with a greater tendency for people in a lower socioeconomic status to engage in health-damaging coping behaviours, diabetes health care services become particularly challenged in delivering effective self-management education. Traditional approaches to diabetes self-management education are especially suitable for highly motivated individuals who have the time, resources, and commitment to participate in the recommended behavioural change or pharmacological strategies. These approaches, however, have been less effective at reaching the most vulnerable groups within the diabetes population (Glasgow, Hiss, Anderson, et al, 2001). Traditional perspectives on diabetes management are based on the assumption that individuals with diabetes would have a greatly improved quality of life if they were to adopt the recommended techniques, interventions and advice offered by health professionals.

However, as Vallis (2004) identifies, “diabetes management is not about the message sent, but rather about the message received” (p.1).

The shift in view from the provider to the patient being the most active decision-maker and problem-solver is central to productive nurse-client interactions as well as in current health-promotion practices (Glasgow et al., 2001). The implications of placing an emphasis on individual responsibility to adopt or maintain a ‘healthy’ lifestyle are primarily two-fold. The first implication is related to cost saving: persuading the public to change their personal behavior and to assume the responsibility for their own health has enormous appeal for governments interested addressing the open-ended expenditures from the fee-for-service reimbursement plan for physicians, rising prescription medication costs, and “high-tech” advancements in hospital treatment (MacDonald, 2002). The second implication is related to the shift in responsibility and accountability from the state to the individual. This has been a recurring theme in the evolution of health promotion with implications for people living with chronic health disease that include greater inequities in access to, and in the quality of, diabetes health care. Also, the effect from privatizing, or making personal, chronic health conditions that are linked to social health determinants serves to make invisible what is not exclusively a personal responsibility.

The Intersection of Schizophrenia and Diabetes

Schizophrenia is a psychotic disorder that affects an estimated 1% of the population and is defined as a six-month disturbance during which two or more of the symptoms—delusions, hallucinations, disorganized speech, disorganized behaviour, or negative symptoms—are present for at least one month (American Psychiatric

Association, 1994). Schizophrenia is associated with significant psychosocial impairment and similar to type 2 diabetes, psychotic disorders are also associated with obesity, sedentary lifestyle and genetic etiology. The etiology of psychotic disorders is unknown, although genetics appear to account for 70% of the vulnerability of schizophrenia (Kendler, 2002). Stress-inducing environmental variables likely account for the other etiological relevance of this condition. The mortality risk for people with mood and psychotic disorders is two- to four-times greater than in the general population (Brown, 2001) although this does include the mortality risk from the nearly 10% of people with schizophrenia who complete suicide (Axelsson & Lagerkvist-Briggs, 1992; Cohen, Test, & Brown, 1990). Diabetes, cardiovascular disease, and infectious diseases account for the majority of the premature deaths in people with schizophrenia (Osby, Correia, & Brandt, 2000).

Antipsychotic medications are useful for treating a range of symptoms associated to psychotic disorders. Indications for antipsychotic medications are becoming more diverse and include the short-term treatment of acute psychotic, manic and psychotic depressive disorders. These drugs are also used for agitated states in delirium and dementia and for the long-term treatment of chronic psychotic disorders of schizophrenia, schizoaffective disorders and delusional disorders. The newer antipsychotic medications, also referred to as “atypical” following a landmark study comparing clozapine to chlorpromazine in which clozapine was found to be “atypical” in having a very low risk of having adverse extrapyramidal symptoms (Kane, Honigfeld, Singer, & Meltzer, 1988), have varying degrees of side effects that include weight gain, hyperlipidemia and hyperglycemia.

Atypical, or second-generation antipsychotic (SGA) medications are generally thought to have greater efficacy for both positive and negative symptoms of the psychotic disorders and to be better tolerated than the older antipsychotic agents because of the lower risk of the extrapyramidal side effects. Although the incidence of movement disorders is less frequent with the SGAs, weight gain is a common adverse effect of many of the newer and some of the conventional medications for treating psychotic disorders (Gardner, Ross, Baldessarni, & Waraich, 2005). Weight gain of more than 7% is often considered to be clinically significant in antipsychotic drug trials – approximately the same amount of weight loss that was achieved by the DPP Research Group (2002) and the Finnish Diabetes Prevention Study (2001) to prevent or delay the diagnosis of diabetes by an average of 58%. In a review of the literature, Allison et al. (1999) found mean increases in weight at 10 weeks of treatment with the SGAs that range from 0.04 kg for ziprasidone to 4.45 kg for clozapine. Taylor and McAskil (2000) in a systematic Medline review of 80 reports mentioning changes in body weight with antipsychotic medications found the risk of weight gain associated with SGAs to be between 14-27% at 6-8 weeks, and as high as 40% by 3.5 years. Clozapine was associated with a 27-60% weight increase at 3-12 months; olanzapine and risperidone were associated with a 15% and 8% increase at 8 weeks respectively.

Hyperlipidemia and hyperglycemia with resulting diabetes has also been associated with the use of SGAs (Gardner, Ross, Baldessarni, & Waraich, 2005) although the rates of relative risk vary considerably according to the type of antipsychotic drug and other patient characteristics. Koro et al. (2002a; 2002b) have estimated that the risk of hyperlipidemia and hyperglycemia associated with modern antipsychotic agents

compared to the conventional antipsychotics, although not well quantified, varies between 0.81 (95% CI 0.4-1.5) and 1.6 (95% CI 0.7-3.8) respectively for Risperidone, and 3.4 (95% CI 1.8-6.4) and 4.2 (95% CI 1.5-12.5) respectively for Olanzapine. In a review by Lean, and Pajonk, (2003) the authors find that the odds of developing type 2 diabetes during the first year of treatment with Clozapine are 7.44 (95% CI 1.603–34.751) compared with patients with psychosis not receiving antipsychotics. The “ranking” of drug according to the likelihood of metabolic risk, as has been published in a consensus paper between a research panel from the American Diabetes Association and the American Psychiatric Association (2004), appears to generally consistent throughout reviews on this concern, however there is conflicting research on the significance between metabolic risk and typical versus atypical drug. The most “at risk group” for metabolic abnormalities on SGAs appears to those less than 40 years old (Sernyak, Leslie, Alarcon, Losonczy, & Rosenheck, 2002). For example, the rate of diabetes for in the general US male population age 20-39 years is 1.1% (Harris et al., 1998) but in patients with schizophrenia age 18-44, the diabetes risk is between 5.6%-6.7% (Dixon et al., 2000).

Sharing the Management of Diabetes and Schizophrenia

Diabetes is a serious medical condition that often requires immediate intervention and life-long management. Schizophrenia is also a serious illness, the management of which usually requires continuation of antipsychotic medications during the course of multiple acute episodes of psychosis and disability, interspersed with periods of less severe symptoms. The effective management of both conditions is dependent on a careful and committed collaboration among clients and their personal and professional support

network that may include the individual with the two conditions, the family and/or community support workers, the family physician as well as psychiatry, endocrinology, mental health, and diabetes education support services.

Individuals with psychotic illnesses, especially those on atypical antipsychotic medications are a high-risk group for diabetes and vascular disease. Self-management of diabetes in this population is complicated by their lack of insight, cognitive deficits, and loss of initiative that are common features of their illness. Monitoring blood glucose levels, calculating and administering insulin doses, or managing food intake are aspects of diabetes self-management that are likely to be beyond the capability of people with active psychosis. Ensuring that patients follow dietary advice is even difficult in the supervised environment of psychiatric units, and unfortunately, patients with schizophrenia often find it difficult to regularly attend outpatient diabetes clinics. The medical outlook for people with diabetes and schizophrenia is therefore not optimistic. Management of schizophrenia should include greater attention to the metabolic risks that appear to be associated to the condition, whether related to diet and activity, to the illness itself, or to the unintended effects from psychotropic medications. Health care teams within the areas of diabetes and psychiatry need to work together to monitor patients to detect early changes in metabolic abnormalities and provide timely supports for the prevention and management of diabetes for people living with schizophrenia.

The problem of managing diabetes for individuals with multiple chronic conditions is not a new phenomenon because the majority of adults with diabetes also have comorbid conditions (Glasgow, Hiss, Anderson, et al, 2001). What is new is the recognition of schizophrenia as a risk factor for diabetes, with the risk having been

identified as at least three times higher than in the general population (CDA Clinical Practice Guidelines Expert Committee, 2003). The American Diabetes Association, American Psychiatric Association, American Association of Clinical Endocrinologists and the North American Association for the Study of Obesity (2004) announced that antipsychotic drugs of the atypical class are associated with an increased risk of diabetes. Other studies on the relationship between diabetes and schizophrenia are more alarming. In a review on atypical antipsychotic effects and diabetes, Jin, Meyer and Jeste's (cited in Rudy, 2002) analysis of 45 reported cases of new onset diabetes found that 84% of cases presented within 6 months of starting therapy, and 59% within 3 months. Results of a 5-year follow-up study of 83 patients taking Clozapine® showed 36% of patients were diagnosed with diabetes that was associated with weight gain and lipid abnormalities (Hagg et al, cited in Rudy).

Comprehensive reviews on studies the effectiveness of self-management training in type 2 diabetes have demonstrated that the effects of physical exercise, smoking cessation, healthful eating patterns, and weight loss, have the potential to either prevent or postpone the diagnosis of diabetes, or to significantly improve both diabetes specific and other general health outcomes (American Diabetes Association and National Institute of Diabetes, Digestive and Kidney Diseases, 2002). People living with schizophrenia often have greater challenges in all or most of the areas that are required for good self-management. In addition to the 'positive' and 'negative' symptoms of this disease that directly interfere with the ability to perform activities of daily living, the population with schizophrenia encounters an additional burden due to the high incidence of substance

abuse and depression, 30% and 50% respectively (Andrews, Goldner, Sagar, & Bilsker, 2000).

For people living with diabetes and schizophrenia, healthcare that emphasizes individual responsibility through the focus on self-management is especially problematic. The more problems people have of a social and psychological nature, the more challenging their diabetes management will become. Therefore, innovative approaches to primary health care are required to reduce the disparities that include the personal, logistical, social, and economic barriers to both self-management practices and diabetes education for this and other vulnerable population groups living with diabetes.

Significance of the Research

The alignment of nursing practice with the dominant medical discourse within healthcare has the potential to disrupt the ability of the nurses to engage with clients, resulting in a limited understanding of the clients' experience. The lack of understanding or consideration by the nurse or other healthcare professional of the significance of the experience of living with chronic illness impairs the capacity to deliver ethical care. This research project has potential to contribute to nursing in direct patient care and in education through supporting and advancing the moral agency of nursing within the context associated with vulnerable populations. This project may also contribute to nursing research by exploring methods, such as the use of conversation, or dialogue, to understand the encounter as it is negotiated by clients living with multiple chronic health conditions.

Relational ethics is useful in considering ethical issues while the relational themes of environment, embodiment, mutual respect, and engagement are appropriate for

attending to quality relationships in all nursing practices. Engagement refers to the genuine attempt to understand the situation, perspective and vulnerability of the client. Relational engagement is a critical theme for effective nurse-client relationships as a mutually satisfactory interpretation of the situation or barrier is discovered. Relational engagement occurs when people are able to find a way to look at an issue together, until they reach a meaning that both can affirm. Referring to Gadamer, Bergum (1989) expands on the logic of dialogue, describing this as the experience of our human ability to listen to one another and the capacity to attend to another. In dialogue, we encounter the opportunity of intersubjectivity, which is to experience and value difference, rather than attempting to find sameness with others. "All relationships as experienced are moral, for in each relationship one is enacting the question of what is the 'right thing to do' for both oneself and for others." (Bergum, p. 485). Ethical action is viewed from the perspective of relationship where moral space is created by one's relation to oneself and to the other. This perspective is particularly useful to this project because the emphasis is not on deciding the goodness or badness of the human actions or character but on acting in ways that lead to goodness that includes dialogue that values relationships with others. In this way, it is my hope that my research process for this project will positively influence the ethical action of health care providers by contributing to a deeper understanding of the population living with the co-morbidities of schizophrenia and diabetes.

CHAPTER 2: The Contextual landscape for Inquiry

There is a crisis of value at work that cannot be resolved simply by appealing to traditional forms of logic and authority

David G. Smith, *Meditations on Pedagogy and Culture*

Kvale (1996) refers to the *traveler metaphor* to describe the interviewer as a traveler on a journey who wanders through the landscape and enters conversation with the people encountered. Kvale's concept of knowledge formation refers to a conversational approach to social research but the traveler's journey, begins before reaching a particular route or arriving at a deliberate destination. Many journeys have brought me to this place in my questioning and desire for understanding. Some of the places I have visited years before are now are partially forgotten. Others I have recently visited are more familiar. There are the numerous people that I have encountered along the way: the people living with a psychotic illness or metabolic disorders or both, their families, the various participants of the interdisciplinary health care teams, the family physicians, and the specialists from other silos of chronic illness care. There are also the regulation signposts that both direct and distract: Clinical Practice Guidelines, and Evidenced-Based Care, Randomized Multi-Site Clinical Controlled Trials and Landmark Research Trials, all promising insurance and clarity. Billboards promoting pharmaceutical assistance dominate the landscape and there are the caution signs: Eat Less, Do More, and Avoid Stress, and the trip destination signs: Heart Disease and Stroke 10 Years ahead, and You Are now Experiencing Neuropathy. I am now prepared to embark on another journey, this time to discover possibilities of understanding the

experience of schizophrenia and diabetes and to create meaning on the encounter of these chronic conditions.

A Journey into Chronic Disease Management

While there is exhaustive research on the diseases of schizophrenia and diabetes separately, I have found no research that explores the experience and understanding on the subject of living with schizophrenia and diabetes. My assumption behind this project is that there is a meaningful and unique encounter for people with schizophrenia who have been diagnosed with diabetes, and that opening this subject to question will contribute to new understanding.

What draws me in to this research question is a sense of something overlooked something that was too complex and ambiguous and made simple through modernity and rationalist thought. This study arrives out of several emerging threads of significance and meaning from my experiences as a mental health nurse, a diabetes nurse educator, and as a healthcare professional concerned for people living with both diabetes and schizophrenia. The main concerns that have brought me to my question are rooted in the discourse within the context of chronic disease management. “Inquiry begins by being ‘struck’ by something, being taken with it...the unanticipated eruption of long-familiar threads of significance and meaning in the midst of a wholly new situation” (Jardine, 1998, p. 40).

My first concern relates to a certain valuing of knowledge that exists within the current context of chronic illness care. Health services for people living with chronic conditions are emerging from medical models that have rewarded episodic care. However, the dominant rationalist view that guides new health care delivery models

continue to produce a form of thinking that inhibits a holistic perspective on health, including the inhibition of ethical action that would originate from a more comprehensive understanding of a particular situation. The consequence of a disengaged perspective obscures not only the experiences of nurses and other health professionals, but also the human experiences of people living with chronic health challenges and especially the experiences of vulnerable populations living with chronic conditions. The medical model and its unquestionable authority silences the embodied, shared and perceptual capacities of those living with chronic conditions and reduces the moral problems experienced by healthcare practitioners to simplified equations. Questions, which encourage understanding, are reduced to problems, which are generally solvable by formulas of their own design. The discourse results in an ideological perspective that has implications not only for the management and outcomes of chronic conditions but for the lived experience of chronic illness and for the manner in which members of the healthcare community portray ethical considerations. My assumption of living with the experience of a chronic illness is that the embodied understanding is generally obscured, or minimized, by the discourse within the dominant medicalization of health and disease.

My second concern relates to the nature and limitations of available research on the relationship between schizophrenia and diabetes, and on the experiences of people who encounter these two chronic conditions. The research terrain where these two health conditions meet is relatively new and it appears to be dominated by a discourse that focuses on psychiatric conditions and metabolic abnormalities relative to pharmacological effects. Categorizing the nature of the dominant discourse within the separate domains of these chronic conditions is particularly complicated due to the

volume of material and the embedded historical, social, political and economic aspects within each context. However, a comparative examination of the experiences of one group (those with metabolic abnormalities and schizophrenia) with experiences shared by another group (those with only metabolic abnormalities) is not my intent.

Philosophical Hermeneutics

Hermeneutics is a theory and practice of understanding and interpretation. The name is derived from legend of the Greek messenger, Hermes, who translated knowledge and understanding between the gods and mortals. Hermeneutics became associated with the interpretation of religious texts in the 17th century as a method of mediating the internal meanings of these texts (Crotty, 1998) but this methodological focus has given way to a hermeneutics that is of an ontological task, or of the question of Being, after the manner of Heidegger (Ricoeur, 1974). Fredrick Schleiermacher (in Paterson & Higgs, 2005) has been acknowledged as the founder of modern hermeneutics and since his time in the 1800s, three themes in hermeneutic inquiry have remained present: “the inherent creativity of interpretation, the pivotal role of language in human understanding, and the interplay between the part and the whole in the process of interpretation” (Smith, 1994, p. 104). The beginning of philosophical hermeneutics dates back to the twentieth century with Dilthey’s work that coincided with the development of human and social sciences. Dilthey began to explore “understanding” as a methodological concept which has its origin in the process of human life itself (Smith). Our understanding of human experience is then related to the degree to which we can show how the manifestations emerge from a lived experience: “Good interpretation shows the connection between experience and expression” (Smith, p. 107).

Edmund Husserl, the most significant shaper of interpretive stream of human science, introduced the notion of the “life-world” to describe our sense of the world as it exists before we speak about it or engage with it. Husserl’s theory of intentionality showed that our thinking and interpreting are “always and everywhere about the world” (Smith, 1994, p. 108) and it is from Husserl that “words like ‘understanding’, ‘interpretation’, and ‘meaningfulness’ are rooted, hermeneutically speaking, in a sense of dialogical, intersubjective, and conversational nature of human experience” (Smith, p. 108). Martin Heidegger, a student of Husserl, was instrumental in providing a new meaning to the term hermeneutics by incorporating this into the philosophical tradition of the question of Being where interpretation becomes the “condition of human self-understanding so that a phenomenology of Being reveals its fundamental mode to be precisely hermeneutical” (Smith, p. 108). Heidegger emphasized the ontological perspective of hermeneutics by stressing the idea of the *understanding of being* occurs before reflection with human experience of the world, taking place in a three-fold structure of attuning to horizons of the past, articulating the situation in the present, and pressing forward to the future (Paterson & Higgs, 2005; Smith, 1994).

Finally, Gadamer, a student of Heidegger, develops his landmark work *Truth and Method* (Gadamer, 1976) and takes on Heidegger’s locatedness of understanding to arrive at the “historico-temporal quality of human experience and the linguisticity of understanding (Smith, 1994, p. 110). Counter to the objectivism that was popular in natural sciences and its claim that knowledge could be free of human involvement, Gadamer reinstated biases or pre-judgements as a requirement for all understanding, that we make sense of our world from within a particular *horizon* which provides the starting

point for our interaction (Smith, 1994). Gadamer introduced the concept of understanding research findings through the “fusion of horizons” with the concern for hermeneutics belonging to the sphere of grammar and rhetoric, where, “language is the medium in which substantive understanding and agreement take place between two people” (Gadamer, 1991, p. 384).

To state that an experience resides in the world, as in a universal phenomenology, is not to suggest that there is a knowledge that is separate from us; rather it is to affirm that there exists a universal experience in which we may share. The significance of this project is to offer possibilities for discovery and understanding of that which is already there, and of that which may be hidden or obscured. It is the horizon of understanding, or the merging of what is known about diabetes and schizophrenia *with* the experience of living with these two conditions, that is of significance to this research. Although this difference between the existence of universal human qualities and shared experiences does appear to be a subtle one, I believe it is significant to my research project—particularly in clarifying the order of abstract things—that reality does not precede our experience of where we encounter an already existing phenomenon. Instead, the phenomenon becomes real through our experience and understanding of it.

Phenomenological research informs the personal insights contributing to one’s thoughtfulness and to one’s ability to act toward others, and it is “a philosophy of the unique, the personal, the individual which we pursue against a background of understanding of the logos of Other, the Whole, or the communal” (van Manen, as cited in Bergum, 1989, p. 44). Phenomenology, according to Heidegger, (1962/1999) denotes, “To the things themselves!” (p. 289). He uses the terms, phenomenon, “that which it

shows itself” and logos, signified basically as “discourse...to make manifest what one is ‘talking about’ in one’s discourse” (p. 292). Phenomenological research is a human science that seeks to interpret and understand, and simply stated, has to do with description of experience (Bergum). Given this understanding of phenomenology, my intent for this interpretive research project is, through language or dialogue, to generate understanding through the mediation of the relationship between the objectivity of the subject of schizophrenia and diabetes, which largely represents the subject matter, and the encounter with this phenomenon as I and participants have experienced it, representing my horizon of knowledge or preunderstanding and the horizon of the participants’ understanding. In this way, my project becomes a hermeneutic endeavor as I am proposing that understanding occurs through a dialogical engagement between the phenomenon and the question. For Gadamer, the hermeneutic problem concerns not the “correct mastery of language but coming to a proper understanding about the subject matter, which takes place in the medium of language” (Gadamer, 1991, p. 385).

Restoring a Situated Reality

Reality is always already interpreted because understanding is situated

Sally Gadow, *I felt an island rising: inquiry as motet*

The scientific method that seeks a univocal reality is useful for such things as understanding the benefit of blood glucose lowering of a particular oral hypoglycemic medication, the cardiovascular risk-reduction of a 10 mm/Hg lowering of systolic blood pressure, or perhaps the relative risk for weight gain associated with an atypical antipsychotic medication. It is not these types of things that I am seeking to disrupt in this research, rather it is as Caputo (1987) remarks, “the work of hermeneutics is to recover

that sense of the world before it was disrupted by objectifying thinking, to restore the sense of what is close before it was made distant by objectification” (p. 96).

Leonard (1989) points out that the accomplishments of traditional science over the past two centuries with regard to disease have been astonishing, although it derives its significance from its meaning for human suffering and capability. Phenomenologists argue that traditional science has served as a theory that has constrained our ability to understand human agency, limited our imaginative ability to generate questions and limited the answers we are able to generate from the questions we pose (Leonard). From a more radical perspective, Caputo (1987) makes the similar statements “thinking means to restore a unity which precedes objectification....we stand always and ready in Being.... and it is just this nearness of the world, this closeness of things—from which modern Technik has alienated us—that must be restored.” (p. 96).

As a researcher, I am approaching this question with a preliminary understanding of the human situation based on the common background meanings provided by culture and language and it is through the hermeneutical approach that I will deepen my sense of the interpretability of life itself. As Smith (1994) reminds us, the hermeneutic tradition is related to our macro-frames that require us to struggle continuously to question what is at work, relying on not only the conventional narratives but also on the suffocated and emerging narratives to, “thereby give voice to and show features of our lives ordinarily suppressed under the weight of the dominant economic, political, and pedagogical fundamentalisms of our times.” (p. 123).

This interpretive work is admittedly influenced by the promises of objectivism as I admit to finding reassurance in the pursuit of univocal expression for a separable reality.

However, my goal is to produce a richness and multiplicity of meaning, not through rational rigor but through other approaches as suggested by Gadamer, (2000) that may include “inventiveness, action, imagination, empathy, emotion, allusion, conversation, and literary composition” (p. 214).

The Hermeneutic Circle

Most authors refer to the hermeneutic circle as a metaphor for the way understanding is achieved through a circular movement between the specific and the general, beginning with the interpreter’s reflections on prejudices or foreknowledge and moving to the general subject, replacing the foreknowledge with new understanding. Schleiermacher’s contribution of the playing back and forth between the specific and general, when applied to the understanding of persons, draws into consideration how language both encourages and constrains a person’s self-understanding (Smith, 1994). The hermeneutic circle was used by Gadamer to describe “the experience of moving dialectically between the parts and the whole” (Koch, 1996, p. 176). Gadamer (1991) takes up the hermeneutic circle not as methodological in nature but of an ontological element of understanding, as a description of the relationship between explanation and understanding that involves seeing something familiar but in a new light, seeking not an absolute truth but an understanding of understanding. For Gadamer, interpretation occurs through the fusing of horizons, or the common language between the observed and the interpreter. The hermeneutical task then becomes to understand how the horizon of the interpreter and the horizon of the interpreted come together to co-create meaning in a particular context.

This hermeneutic inquiry is concerned with the experience located in the world shared by people living with both schizophrenia and diabetes, and with the interpretive process as a method of interacting with the meaningful set of relationships, practices, and language that become our phenomenological world. “Understanding the lived experience is about understanding the structures and relationships that construct our lived realities” (Ceci, p. 68, 2000) and this serves to disclose the obscured meanings related to the question. This project is grounded in phenomenological research, specifically, with the subjective experiences of others and my own informing, or speaking to, the experience of that I am seeking to question, but it is more than this. It is also the interpretation of the situatedness or location of the experience that is lived. I am attempting to use hermeneutics not to explain or describe the subjective experience, but to open up the experience itself to possibilities for understanding.

Chapter 3: Approach to Inquiry

The real power of hermeneutical consciousness is our ability to see what is questionable.

Hans-Georg Gadamer, Truth and Method

“Inquiry begins by being ‘struck’ by something, being taken with it...the unanticipated eruption of long-familiar threads of significance and meaning in the midst of a wholly new situation” (Jardine, p. 40, 1998). In this interpretive research project, I will explore the possibilities of understanding the experience of living with diabetes for people with schizophrenia. The characteristics of the question, as offered by Burch (1986) are significant to this project: a concern for a matter in which we are involved in and pertaining to our world; a radical and comprehensive context of understanding rather than seeking a definitive answer; a concern for the elucidation of meaning; and a concern for who we are as human beings. “In questioning, effect and answer are the same, namely a transformation of being” (Burch, p.7) and it is the transformation of understanding (or thinking) on the subject of people living with schizophrenia and diabetes that I hope to accomplish in this inquiry. “It is this—adding to the understanding of our lives—that is the goal of interpretive inquiry” (Jardine, 1998, p. 43).

Generating Text through Hermeneutic Conversation

To have a conversation with another with the goal to understand a subject, such as encountering chronic illness, requires a folding and unfolding of myself, each time opening another part of myself with which I have had an experience and with what I seek to have a conversation about. As I engage in a conversation, I find that I am at times directing it, sometimes remaining with the topic at hand, and other times following a path

or discovering that which has emerged, like a discovery found on a journey. Kvale (1996) uses a metaphor as the interviewer as a traveler who wanders through a landscape entering in conversation with people along the way. The image of interviewer as traveler is particularly useful for hermeneutic inquiry in depicting the way the text emerges in the process of the conversation; co-created and unfolding in an unpredictable way. The generation of text then, is not a process where the “data” are gleaned from participants’ behaviours, statements, or presentations and then interpreted later by the researcher. Entering in conversation, I cannot know where it will take me. I must attempt to allow the conversation to take the lead and let go of my preconception of what the conversation should be, or where it should go. My question then at the outset of this research journey may not remain the question that I am later left with as my conversation continues and evolves along every turn, every discussion and rediscussion. If the process of interpretive work is, as Gadamer (1991) and Jardine (1998) both suggest, one of being fundamentally accidental—more of a method of stumbling than an art or technique—then I wonder how it is possible to set out to understand one thing as opposed to understanding anything. Perhaps it is as Caputo (1987) states, “knowledge, accordingly, is not a discovery which forges ahead—for that would be real movement—but a recovery, a recollection which recoups a lost cognition” (p. 13). This speaks to the nature of the hermeneutic conversation, that it is about a given subject, but that it belongs to a form of inquiry that is solely determined by that which is co-constructed between the interpreter and interpreted, and in this way, the goal of hermeneutic inquiry becomes one of evoking interest, wondering and understanding. The hermeneutic approach does not position the final authority of concepts within the concepts and constructs themselves but “within the

dialogically derived at agreement of people who consent to them” (Smith, p.119):
 meaning is arrived at relationally rather than absolutely.

The data that informs this inquiry are largely derived from the transcription of the recordings with participants and includes the words spoken between us and a record of significant nonverbal aspects of our conversations. Other text for this inquiry includes the literature that is relevant to the question and to the co-constructed text from my conversations with participants. Additional data will include notes taken from conversations with professional colleagues that have served to further inform my understanding of the issues that have emerged during the interpretive phase of this project. My own reflexive and interpretive writing will form another part of the text of this inquiry and will account for what Smith (1994) states is the transformations undergone in the process of inquiry; a showing of a dialogical journey.

Interpreting Texts

“To interpret means precisely to bring one’s own preconceptions into play so that the text’s meaning can really be made to speak for us.”

Gadamer, *Truth and Method*.

Scheiermacher (cited in Gadamer, 1976/1999) defined hermeneutics as the art of avoiding misunderstanding, “To exclude by controlled, methodical consideration whatever is alien...misunderstanding suggested to us by distance in time, change in linguistic usages, or in the meanings of words and modes of thinking” (p. 341). Jardine (1998) describes interpretive research as beginning with a different sense of the given, which refers not to an instance severed from ambiguity and our familiarity with it, but an instance that is complete with the original, ambiguously alluring familiarity that is

recognizable when we hear of the story of one's transformation. Jardine describes how text is analyzed in interpretive research to make a claim of truth:

The task of interpretation is to bring out this evocative given in all its tangled ambiguity, to follow its evocations and the entrails of sense and significance that are wound up with it. ...In this sense, our unanticipated, unmethodical being in the world can, quite literally in certain circumstances, make a claim to truth (p. 40).

In my analysis of the data through this form of interpretive inquiry, I am not intending to produce a unity of meaning or a saturation of coded words or identifiable themes. Rather, I am wishing to explore what understandings are made possible. "I can learn the ways of this instance only by taking the time to experience where it 'goes' and thereby seeing to what territories and terrains it belongs" (Jardine, 1998, p. 45). Analysis is essentially the hermeneutic circle that proceeds from a naïve understanding to an explicit understanding that emerges from the interpretation of the text (Streubert & Carpenter, 2003).

This project is also an attempt to explore how interpretive inquiry is able to address an event such as that of understanding chronic illness: "such incidents can have a generative and re-enlivening effect on the interweaving tests and textures of human life in which we are all embedded" (Jardine, 1998, p. 34). This is perhaps what Smith (1994) is referring to in, "Hermeneutically...I always interpret others from within the frame of our common language and experience so that whatever I say about you is also a saying about myself" (p. 127). A good interpretation then, according to Jardine (1998) is not definitive and final but one that opens outward to "the possibility and the responsibility of *returning*, for the *very next instance* might demand of us that we understand anew" (p. 43).

Smith (1994) notes that the mark of good interpretive research “is the degree to which it shows understanding of what it is that is being investigated” (p. 125), and as the social philosopher, Alan Blum (in Smith) puts, good hermeneutic writing is “strong”, “its desire is to provoke new ways of seeing and thinking within a deep sense of tradition, bringing about new forms of engagement and dialogue about the world we face together” (p. 127). Understanding and interpretation are bound together and occur not within the written text but within the reading of it, through the interaction or dialogue with the text by the reader: “understanding is already interpretation because it creates the hermeneutical horizon within which the meaning of a text comes into force” (Gadamer, 1991, p. 396).

Hermeneutic Writing

If he indeed is wise, he does not bid you enter the house of his wisdom, but rather leads to you to the threshold of your own mind.

Kahlil Gibran, *The Prophet*

Good hermeneutic research shows an ability to read from inside out and from outside in; a narrative construction that can be entered and engaged creatively, containing a received understanding that can be interpreted or re-interpreted to fulfill human responsibility in the taking up of this task (Smith, 1994). Hermeneutic writing is an invitation to others to be engaged dialogically into the subject in which it speaks. Understanding occurs through interpretation, which is a continual process of writing, reflecting, rewriting, questioning, and continuing conversations, and is therefore never final. Interpretive inquiry is in this way frustrating as I am aware of the limitations of this work but this is perhaps not a limitation, rather a realization that there is so much more to

say and so many more conversations to have on this or any subject. This too is a reflection on the deepening of one's sense of the interpretability of life itself (Smith, 1994), and the taking up of the interpretive task rather than accepting the truths or ideologies that disrupt our creative ways of thinking and of questioning.

Hermeneutics is about creating meaning and not simply reporting on it (Smith, 1994) which is to say that the task concerns not the expression of what has been said about a particular subject but about a desire to provoke an engagement with the subject through what is written. Throughout my writing for this interpretive inquiry, I have been aware that all interpretation occurs in the medium of language. As I read and re-read each section of each chapter, I am struck by the variation in the degrees of my own engagement and I expect that this variation will occur with other readers who interact with this text. I am concerned about aspects in the reporting of things, such as my writings on the medical and pathophysiological aspects of diabetes and schizophrenia, may not draw the reader in to form a participation with the text to provoke new or significant meaning. Yet I have left this section that represents my foreknowledge of why this issue is significant to me and why I believe it to be significant to others.

There is also the integrity of hermeneutic writing that is achieved through accounting for the process of how I came to understand this subject as meaningful and through providing the reader with sufficient information about this research process so as to make accessible the trustworthiness of this work. My writing should be clear enough to provide credibility to the subject and to the participants' and my experiences with it, but be open and ambiguous enough to encourage the readers to arrive at a new interpretation of their own.

Integrity of the Research

“A good phenomenological text has the effect of making us suddenly “see” something in a manner that enriches our understanding of everyday life.”

(van Mannen, p. 345, 1997)

Ensuring quality in interpretive hermeneutic research requires attention to the three main criteria of credibility, rigor, and ethical behavior. Credibility refers to the truth, value, or believability of the findings or the activities that increase the probability that credible findings will be produced (Streubert & Carpenter, 2003). An important way to achieve credibility is to enact the research philosophy in a way that is adequate to the problem or situation being explored (Patterson & Higgs, 2005). Hall and Stevens (1991) offer the concept of reflexivity, the assumption that knowledge is held to be jointly constructed between researchers and participants, as a means to make research believable and plausible. Emden and Sandelowski (1999) suggest the “criterion of uncertainty” (p. 5) as criterion for addressing rigor in qualitative research that provides an acknowledgment that the claims about the research are at best tentative.

Credibility in qualitative research also refers to the appropriateness between the research methods and the research question, and to concepts of authenticity, plausibility, and trustworthiness. The process of hermeneutic analysis contributes to the transparency, trustworthiness and plausibility of the research findings and interpretations (Patterson & Higgs, 2005). The analytical process of using the hermeneutic circle, the dialogue of question and answer, and the fusion of horizons will assist in making the analytical process in this research project transparent to the reader.

The issue of rigor in relation to qualitative social research requires a critical focus on the inadequacy of applying quantitative concepts to evaluate most forms of qualitative research. The application of evaluation criteria from one paradigm of inquiry to another, and preoccupation of qualitative researchers with methodological rigor are both problematic and a legacy of the positivist paradigm (Koch & Harrington, 1998). The methods for ensuring credibility of qualitative research, including the notion of bracketing assumptions to ensure pure description of the data, and returning data to the research participants for confirmation of the findings (Streubert & Carpenter, 2003) are contradicted by the philosophical assumptions of Gadamerian interpretive inquiry.

There are several ethical requirements associated with this and any qualitative research study that include informed consent, participant-researcher relationships, confidentiality, anonymity, sample size, and data analysis (Streubert & Carpenter, 1999). I attempted to achieve the profoundly ethical aspect of hermeneutical inquiry: that a researcher is prepared to deepen his or her own self understanding in the course of research (Smith, 1994). In interpretive research, the course of one's journey should also be in some way visible so that those who follow are able to retrace the research trail. I maintained an interpretive journal of reflexive writing as well as a record of the paths of my decision-making, not only to attempt to reveal the transformation of self that occurred in the course of this inquiry, but to capture my situatedness and hold visible my journey throughout this project.

The traditional method of seeking informed consent does not allow for consideration of the unpredictable and developmental nature of qualitative inquiry (James & Platner, 1999). In this research project, I anticipated that the risks to participants would

be minimal, and mainly related to their emotional responses to talking about difficulties of their lives. Because qualitative research is conducted in a context where unexpected events and consequences occur, informed consent should be an on-going process, described by Streubert and Carpenter (1999) as process informed consent. In obtaining consent, I informed participants of my interests and intentions, the expected processes of the inquiry and my intentions related to understanding that is generated from my interpretations of our conversations. I initially obtained consent from participants in written form (see appendix A) but I reviewed this again at the beginning of the conversation. At varying points in the process, particularly when unexpected events or consequences may have occurred, I was prepared to evaluate the participants' consent to continue with their participation in the study. I informed participants of their choice to terminate their involvement with this research at any time, including up until the writing of this thesis.

In communicating risks and benefits, I explained the minimal risk from this research that includes potential for emotional suffering related to traumatic events that emerge through the process of telling one's life story. Although I was prepared to interrupt the interview to be available to assist participants with debriefing the event, this was not necessary. I also encouraged participants to contact someone from their health care team (case manager, support worker, psychiatrist, or physician) if they found themselves to be distressed or agitated during or following the interview.

It is necessary to include members of vulnerable groups in this research because it is these conversations with people who are vulnerable—those living with a serious mental illness and living with or at high risk for metabolic disorders—that I believe are

essential for the generation of new understanding on this subject. I did not involve any participants who were in acutely ill states (actively psychotic or delusional), and for those who may have displayed active psychosis or agitation during the interview, I was prepared to terminate the conversation and inform the participant's case manager, support worker, or care giver as available.

The data generation proposed for this research project involved one-to-one interviews that necessitated an open and personal relationship between the interviewer and participant. There was a risk that the boundaries of the interviewer as researcher, or interviewer as therapist or counselor, became blurred and I therefore took special care to give precedence to the participant's welfare over the research. As Streubert and Carpenter (1999) suggest, following the closure of the interview (or conversation), researchers should summarize the issues of concern that have emerged during the interview and should also provide follow-up. A participant who has a preexisting relationship to the researcher as a client receiving diabetes education may perceive a penalty or potential loss of benefit if he or she would decide to withdraw from the study, even if this is clearly indicated otherwise in the participant consent form.

Every effort was made to ensure participants confidentiality and anonymity and I informed the participants of this orally and in writing (see Appendix B). The participants' real names were not used to identify the transcript or recorded conversations that I retained for the duration of this research. Recordings of conversations were electronically stored and password-protected, and participants were informed that all identifying data (recordings, written text and electronic data) will be disposed of after the completion of this project.

Coming Together

*If I give you my truth and receive no truth in return, then there can be no truth
between us.*

Thomas Merton, *Emblems of a Season of Fury*

Access to the potential participants for this research project was made possible through my relationships with clients and staff that had developed over five years of working in the psychiatric setting, and from various forms of contact throughout the initial research process related to this thesis. Over the course of the 18 months that preceded my proposal for this project, I held meetings with staff from a day treatment program that provided a needs assessment of the population living with schizophrenia, offered two presentations to the various disciplines in mental health on the risks and recommended screening for metabolic abnormalities for patients living with serious mental illness, and organized a focus group consisting of patients with schizophrenia who were concerned about weight gain or the risk for diabetes.

Regular meetings involved two staff, the coordinator and one of the group facilitators, from the psycho-social rehabilitation day hospital program located in a psychiatric facility in British Columbia. The purpose of these meetings was primarily to raise awareness among the mental health professionals on the need to address metabolic related risks for people with severe and persistent mental illness, to identify issues shared by this population that contribute to the challenges of diabetes management, and to identify the existing support groups, programs or services that could possibly address each challenge. The outcome of the meetings was very promising in that the needs that were identified for this population had been attempted or were already in place through a

variety of support groups and community programs such as smoking cessation, stress management, physical activity, and illness and medication knowledge. A wellness group for example had been tried but the attendance was poor due to client dissatisfaction with the closed group structure and what the coordinator of the day hospital believed was, “a need to get programs out of the ghetto of mental health and into the community” (personal communication, September 15, 2005). Deficits in services between mental health and diabetes and nutrition programs were also identified during our meetings. These included inadequate nutrition services for needed education and support to this population within the mental health setting, and budget limitations and program inflexibility in diabetes services for providing needed support to clients within the mental health setting. Knowledge deficits were evident among health care professionals in diabetes and mental health services with staff from mental health requiring education on the risks for metabolic abnormalities and the management of these conditions, and staff from diabetes services requiring training on how to provide clients with severe mental illness education and support for diabetes self-management. At the conclusion of our meetings, a plan was developed between the coordinator of the day hospital, the registered psychiatric nurse who was the group facilitator, and myself to utilize existing support groups and programs but to modify the content and design to help address the unique health challenges of this population related to the risk and management for diabetes. The loss of a the group facilitator, however, led to a disruption in our plan to move ahead with fund raising and further program redesign within the day hospital program.

After providing the presentations to in-patient psychiatric nurses, psychiatrists, social workers, and case managers from the community mental health services, I held a focus group with assistance from case managers who were able to recruit clients who were interested in learning more about diabetes and their diabetes risk factors and willing to share their thoughts on how to meet some of their needs. From the focus group of a dozen participants, it became very clear to me that many lacked basic knowledge of diabetes and how to prevent this condition, although most were aware that people taking antipsychotic medication were at higher risk for diabetes and weight gain compared to the general population. Over the next several months I completed my research proposal and ethics application and was ready to begin the recruitment process.

I obtained a joint ethics approval from the regional Health Authority and from the University of Victoria before making initial contact with potential participants for this study. It was my intention to seek recruitment from several agencies in the Health Authority and these included in-patients psychiatric units, the day hospital (where both in-patients and out-patients attend life-skills groups), a community mental health centre (specifically targeting the schizophrenia service case management team), two psychiatric residential group homes, and a tertiary psychiatric care facility. I offered brief in-services on my research to care providers to inform them of the nature and purpose of this study but I did not expect that health professionals would be assisting with recruitment, other than to assist with posting of my research poster (see Appendix A) and to serve as a contact to arrange meetings with potential participants.

Participants were selected through purposive sampling as is appropriate in qualitative inquiry (Polit & Beck, 2004), yet there are different kinds of purposive

sampling that require different minimum sample sizes (Sandelowski, 1995). The method of sampling for this study requires participants based on their particular knowledge for the purposes of sharing that knowledge (Streubert & Carpenter, 2003). I expected that I would be able to keep the sample size to between six and ten participants, which is consistent with adequacy and appropriateness for qualitative studies (Polit & Beck, 2004). Hermeneutic inquiry is not made valid by the numbers but through the depth of examination of the topic under study and the extent to which the interpretation offers understanding (Smith, 1991). An adequate sample size in qualitative research is one that permits “a new and richly textured understanding of experience” (Sandelowski, 1995, p. 182).”

I invited participants who had a diagnosis of schizophrenia and who also had been diagnosed with diabetes or pre-diabetes, or expressed a meaningful concern about the risk for this metabolic condition, which might have included significant weight gain. I did not request access to patients’ medical records to verify participants’ diagnoses, although in conversation, some participants chose to share aspects of their medical history that did give me question about the accuracy of their diagnosis. In speaking to Laurie, for example, her description of her psychiatric condition appeared to be related to depressive symptoms only but she did state that she has experienced brief periods of psychotic symptoms.

Four out of the seven participants were known to me either through my previous experience as a nurse on the in-patient acute care psychiatric unit or as a case manager in the schizophrenia service of the mental health centre. Joe Bell and Al resided at one of the psychiatric group homes and I had become reacquainted with them during my

consultation work for one of the graduate courses. Greg lived at a tertiary care facility at the time of our meeting and I have known him from his previous admissions to the in-patient psychiatric unit and from his frequent appointments to the Diabetes Education Centre. John was one of my clients when I was working as a case manager in the schizophrenia service and he had contacted me from one of the recruitment posters that were posted in the day hospital program. Matthew, Laurie and Randy were not known to me. Matthew and Laurie expressed their interest in this research to their case managers with whom I have had regular contact since working in mental health and throughout this research project. Randy had been in hospital for six months at the time of our meeting and was waiting for placement in a group home. Randy had expressed his interest in being a participant for this study to one of the psychiatric nurses who then contacted me to arrange our meeting.

It was my intention to meet at least two times with each participant who had agreed to take part in this study. The first meeting was to enable the development of a relationship between participant and researcher to establish a degree of mutuality and provide an opportunity to address any questions regarding the intention of this study or consent form. After the initial telephone contact with each participant I arranged to meet to offer an explanation for my interest in this research topic and to review the consent form. These meetings also served to establish some form of familiarity between myself and the participants which I had hoped would make for a more comfortable conversation at the next meeting. I encouraged the participants to take their time with the consent process and consider their decision about participation over the next few days before agreeing to take part in this study. Four of the participants wished to sign the consent

process at the first meeting and three agreed to wait for the next meeting before returning their consent forms. One man who had initially agreed to participate declined after our first meeting. During our initial conversation he revealed to me that his many years of neglecting his diabetes had resulted in his blindness. He apologized for withdrawing from the study, stating that it would cause him too much distress to recount the years of his diabetes that he should have looked after things differently to prevent the loss of his sight.

The second meeting with participants involved the recorded conversation, which I expected would be no more than an hour in duration. I anticipated the possibility of returning to meet a second time with some of the participants, expecting that there would be more of their experiences to be explored than could be covered in an hour. I had considered that shorter meetings would be more appropriate for some, particularly if our conversations proved to be emotionally challenging. It turned out however that the single meeting was sufficient as with each participant there came a point in our conversation that there seemed there was no more to say on the topic. This does not mean that had I returned again, or posed questions on other aspects of their lives that there would be no more to be said, or when re-listening to or rereading our conversations, that there were not opportunities for further exploration that I had missed. My decision to not meet a second time with the participants did not materialize all at once, but rather grew throughout the process of meeting with others for our conversations and reflecting on the texts that emerged along the way. I acknowledge that through repeated meetings there is a possibility for the hermeneutic process-the hermeneutic circle-to be more fully experienced, as described by Gadamer (cited in Fleming, Gaidys & Robb, 2003) where feedback and further discussion takes place to create a shared understanding between

researcher and participant. I decided however that because of Gadamer's assumption that understanding is dependent on a particular historic context, meeting with participants several times would only prove this point: each meeting and conversation would be new and therefore offer a new understanding as both participant and researcher would arrive with a different preunderstanding. I decided it would be sufficiently meaningful to arrive at a shared understanding from one meeting, realizing too that in the encounter of the experience of living with schizophrenia and diabetes, each participant will be at a different point in the journey with this phenomenon, and I believed it is also possible that in this first meeting and conversation, this may have been the first opportunity for participants to enter into discussion on this matter. I was looking to arrive at an understanding of a particular moment of each participant's journey as it relates to living with schizophrenia and diabetes.

Meetings were arranged at a mutually agreed upon time and place but I left the choice of location mainly to the discretion of the participant as I believed this to be an important factor in establishing a degree of comfort and trust. With the exception of the two participants living in the group home who were comfortable meeting in a common room that allowed sufficient privacy, two participants chose to meet in their own homes. One participant expressed his reason for choosing to meet in the borrowed space of the day hospital, revealing his difficulty in keeping his apartment organized. One participant who was in hospital waiting placement in a group home and another participant who was living in her own apartment were met in interview rooms of the hospital or community offices.

I made a deliberate effort to follow the conversation of each participant but I was conscious that my journey with them was not without a predetermined plan or direction with regard for what I was hoping to experience. As Fleming, Gaidys, and Robb (2003) emphasize, it is necessary for researchers to keep themselves and participants oriented to the subject under study. Before each conversation I provided the participants an overview of the purpose of my research, offering a brief explanation of the reason for my interest in this topic. I was satisfied that each member understood that my research was significant to their concerns and that they believed that their experience they were about to share was meaningful to this study. I began the conversations with asking participants to tell me something about themselves or their experiences with their psychiatric disorder.

Conversations generally flowed according to participant's responses and to my questions that were related to the research topic or my comments that were required to redirect the conversations back to the subject of the study. In my initial conversations I sought more specific description of the participant's experience with their mental illness, trying to understand how this interacts with their ability to manage diabetes or the risk for this condition. During later conversations I altered the questioning somewhat, exploring not the course of positive or negative symptoms related to their diagnosis of schizophrenia, but rather the description of everyday life on good and bad days.

Conversations with participants were recorded onto micro cassette and transcribed verbatim to written text, with each file stored in electronic format. During and following each conversation, I made notes to gather information about the experience that was not captured in the audio recording, such as the description of the setting, the participant's mannerisms or gestures that I thought relevant, and thoughts that I had during and

immediately after these conversations. All data and printed text was password-protected or locked in a filing cabinet or office drawer with access only by myself. There were no original names of participants attached to any document or file to further protect participant confidentiality. I initially intended to retain contact names and telephone numbers of participants in the event that I needed to return to the participants for feedback and further discussion, although this experience of Gadamer's hermeneutic circle, as suggested by Fleming, Gaidys, and Robb (2003) did not seem feasible or appropriate in this study.

The Participants

My intention here is to provide an introduction to the participants who were involved in this research. The descriptions here will be familiar to nurses and other health care professionals who work with clients with mental illness or with diabetes. While the following descriptions of these participants represent a type of "factual" information or possibility of how we can know another, it also serves as a point of departure into the possibilities for what follows, or the opening of another way we can know someone.

There are other participants that helped inform this study but they were not part of those involved in the formal consent process or in recorded conversations. The other participants were my colleagues who were willing to talk to me on this subject along the way. They helped to inform this subject, of the encounter of schizophrenia and diabetes, and to help provoke my own preunderstanding as these "become discernable through confrontation with different beliefs such as opinions of other researchers, colleagues or traditional texts" (Fleming, Gaidys, &Robb, 2003, p. 117). To protect the anonymity of

my colleagues, I have given them pseudonyms. Conversations were recorded in note form and kept along with my journal entries.

Joe Bell

Joe is a 60 year-old man living in a psychiatric group home with five other men, all who have persistent and severe mental illness. Joe has been living with diabetes for the past 28 years and with paranoid schizophrenia for over 40 years, diagnosed with this at the age of 16. Joe comes to this inquiry through a poster that he saw on the notice board of the group home where he lives. He has diabetes and requires multiple daily blood glucose monitoring and insulin injections that he is able to do relatively independently. Joe's independence means that he tests his blood glucose levels and takes his insulin dose according to a schedule that his physicians have ordered for him. Joe also makes the regular visits with his endocrinologist and physician for monitoring of his diabetes that includes routine blood work and screening for diabetes-related complications. Joe has not lived on his own without care giver support since he was diagnosed with schizophrenia about 40 years ago and it has only been in the last 11 years that he has been free from acute psychotic episodes or prolonged agitated states that would require hospitalization for management of psychiatric symptoms. He attributes this to his success in quitting the alcohol intake and since this time he has lived in the supportive environments of the psychiatric group home.

Joe did not talk about his family or friends during the interview but he did describe the relationships of trust between certain care providers; his family physician, his endocrinologist, and his psychiatrist. Throughout the conversation with Joe, it became clear that he is a cooperative person and one who has found his own faith in Jesus, his

“higher power” that has enabled him to find the strength to help him stop drinking that has in turn made it possible to better look after his own health including taking care of his diabetes. Joe was looking forward to moving into his own apartment where his level of independence and self-responsibility will increase. He will still have some level of support from psychiatric rehabilitation workers, but he will be responsible for his own cooking and medications. Joe told me he is not concerned about this because he has been learning how to cook while at the last two group homes, and that his insulin administration and blood glucose monitoring is an established routine.

Al

Al is a 46 year-old man also living in a group home for people with severe mental illness and states that he has been living with schizophrenia since he was 21 years old. According to his support workers Al has not required rehospitalisation for his psychiatric condition in the several years of being in the group home. I was told that the support provided by the group home has worked well for Al, as he has not been reliable with taking his oral medications for his psychiatric condition when living on his own. I had known Al since 1997 at which time I was working as a psychiatric nurse in the acute care ward of the local hospital. By the year 2000, I knew Al as his case manager and at this time he was living in a subsidized apartment while receiving meals at the hospital that was adjacent to his apartment. Al was not psychiatrically stable then, and as he admits in the conversation for this research project, he was angry and unable to maintain appropriate interactions with others when not taking his oral medications. Long-acting depot anti-psychotic medications offered some degree of emotional stability but this medication was not as effective as the newer medications that at the time were only

available in oral form. Al therefore cycled between levels of mental instability that were not severe enough to justify admission to hospital but significant enough to prevent him from functioning independently without continual support from case management. Al was opposed at the time to moving into the supported living arrangement of a group home because of what he perceived were unnecessary restrictions on his freedom to choose when to wake, when to sleep, what to spend his money on and how much to spend, and so on. Al is happy where he is now, even if the group home with the perceived restrictions and expectations is where he did not want to go.

Greg

Greg is 29 years old and at the time of this conversation he was living in a tertiary psychiatric care facility. Greg was living in one of the on-site apartments for residents who were nearing discharge into the community, possibly into a group home or to an independent living arrangement with regular case worker support to help prevent rehospitalisation. Greg has been living with schizophrenia for about 12 years, diagnosed when he was in grade 10. Greg is also living with diabetes, a condition he has had for about four years. He was diagnosed with type 1 diabetes and like all people with this type of diabetes, requires multiple daily injections of insulin and routine blood glucose monitoring to stay well.

Greg is known to me from my years of working on the in-patient units at the psychiatric facility and more recently through his regular appointments at the diabetes education centre at the regional hospital. He is repeatedly admitted to hospital after presenting to the emergency department for diabetic ketoacidosis, with blood glucose readings frequently over the critical range of 30 mmol/L.

John

John is in his late twenties, or perhaps in his early thirties, and has been living with schizophrenia for about 7 years. John, like Al, does not yet have diabetes but due to his family history of this condition, he is concerned that he is at risk. John was the only participant who called me directly to inquire about participating in this research. John is interested in participating in this research because he hopes that in understanding the challenges faced by those living with schizophrenia and the risk for diabetes, health care professionals will be more able to provide support for this population.

John has maintained an ability to live relatively independently in his own apartment that was arranged and set up for him by his supportive parents after his first hospitalization for schizophrenia. John has needed re-hospitalization due to reoccurring episodes of psychosis but it has been over a year since he was last admitted to the psychiatric unit. John's struggle is with finding and maintaining a routine that will keep him occupied in a meaningful way. His attempts at working, whether at volunteer jobs or paid jobs, and at maintaining a routine of regular exercise are interrupted by the challenges of his emotional "ups and downs". John finds it exceedingly difficult to stay meaningfully connected to activities and worries too about how he is perceived by others, which adds to the barriers to maintaining healthy routines.

Randy

Randy is 22 years old and has been living with schizophrenia since he was 18, or about 5 years, he tells me. Randy had expressed interest in this research after seeing the recruitment poster on the 6th floor, where day programs are held, and during our initial meeting before this conversation he had expressed concern about his weight gain and the risk that this might have on diabetes. Throughout this conversation however, Randy no

longer spoke of these concerns. Although he had gained a considerable 60 pounds since starting on the antipsychotic medications his concerns were now focused on the current restrictions of hospital life and the anticipated restrictions of group home life that was waiting for him after discharge.

Laurie

Laurie is 41 years old and had her first psychotic break when she was 30. She was working as a psychiatric nurse at the time and was off work for two weeks during her first break. She had another episode at the age of 32, another at 33, and her most recent and severe episode three years ago, when she was 38. She is on several classes of psychotropic medications that include an antipsychotic, an anti depressant, and an anti convulsant or mood stabilizer. Her father developed diabetes but this was related to the chemotherapy for leukemia and therefore likely steroid-induced diabetes, so her family risk for diabetes is unclear. Laurie's main concern from her diabetes risk comes from her weight gain that is related to her medications. Over the nine years with mental illness she had gained 100 pounds, lost 40 and regained another 70, now at 270 pounds from a starting weight of 140 before her mental illness appeared. With this catastrophic weight gain Laurie has legitimate concerns about the effect of this on her health. She knows diabetes is related to obesity and it is with this concern that she had agreed to take part in this research. Laurie is no longer hopeful in her own abilities to get control of her weight and she has arranged, through her case manager's support to come to the Diabetes Education Centre for education and advice on how she might tackle this concern.

Mathew

Mathew is 45 years old and living on his own in his subsidized apartment. It has been about 5 years since his last hospitalization but he implies that he has had several admissions to the psychiatric facility since his first episode in 1985. Mathew did not initially tell me that he had been diagnosed with diabetes. He did say that he was concerned about his weight although he would not tell me how much he weighs or how much he wants to lose. One of the few things in his bare apartment is a stationary exercise bike that he estimates he uses either not at all or one time in the week.

Laurie is the only female of this study and I wonder again whether this is significant or meaningful. I feel that it is, as though having a female or two in the mix would somehow serve to provide an additional perspective although I do not know what this would be. I decide that what is likely more significant was the difficulty in recruiting people for this study, a process that began in November of 2006 and came to a completion at the end of June of 2007. From the focus group I held in the summer of 2005, from meetings with others living with schizophrenia and diabetes, through the clinic where I work as a diabetes educator, or through the meetings at the group homes during the course work that preceded this research, I know that many were interested in participating in this research. I come to an understanding on this subject matter, that the challenges of recruitment for this research are reflected in the challenges of those living with schizophrenia: following through with an activity is met by any number of barriers.

That the participants came to me only through a significant connection, I assume has something to do with trust, familiarity, or with being willing to help out in some form of reciprocity within the caregiver-client relationship. I believe I had underestimated the

degree of the unpleasantness of talking to a stranger about the devastating losses of schizophrenia and what it would mean to try to look after another disease that requires the skills and resources that are often deficient due to the many barriers of a psychotic illness.

Chapter 4: Schizophrenia and Diabetes: The inner Circle

The fact is that the problems of verbal expression are themselves problems of understanding (p. 369).

Gadamer, *Truth and Method*.

Starting Out

One of the most significant critiques of interpretive research speaks perhaps to the charge of radical relativism, that “if any interpretation is possible then no interpretation has any particular value?” (Smith, 1992, p.253). In a critique against the ideal of objectivity, Heidegger rejected the traditional account of cultural activity as a search for universally valid foundations for human action and knowledge and developed an epistemology of which all meaning is dependent on context and a particular horizon, perspective, or background of intelligibility (Sampaio, 1998). Gadamer also shares in this critique of objectivity describing the cultural activity as an endless process of fusions of horizons. “Through an endless, free and unpredictable process of fusions of horizons, our personal horizon is gradually expanded and deprived of its distorting prejudices in such a way that the educative process (Bildung) consists in this multiplication of hermeneutic experiences [writer’s parentheses]” (Sampaio, p. 1). Gadamer’s hermeneutics, according to Sampaio, echoes Heideggerian holism—the thesis that all meaning depends on a particular interpretive context—but also addresses the relativity of the human existence and avoids the danger of radical relativism.

My second anticipated challenge regarding the concept of interpretation lies in the assumption that what is spoken or shared by others is, without the process of

interpretation, obscured and not yet understood. As Jardine (cited in Gadaw, 2000) portrays, “Interpretively speaking, each thing that comes to meet us is what it is not.” (p. 210). This is the disturbing nature of interpretive research: that which comes to meet us can always be reinterpreted, and therefore understanding is never complete. Therefore, I cannot anticipate the features of my writing that will reveal reliable understanding and features that reflect peculiarities of my own experiences. My challenge is perhaps articulated in the paradox, “what interpretation is henceforth about is not me and my past experiences, but that of which I have had certain experiences” (Jardine, 1998, p. 44). My goal is then, as Gadamer (1991) identifies, to participate in the subject matter under discussion, or in the interpretation of the text, and find the common language that coincides with the very act of understanding.

The third challenge of this interpretive hermeneutic inquiry is to construct the radical shift on the conceptualization of the authority of knowledge. Coming to an understanding on a particular subject matter through interpretive inquiry does not result in a complete, final, or authoritative view of the issue. That is not the goal of interpretive work. The problem with the pursuit of knowledge by forms of inquiry that employ univocal “key terms” and “coded words” lies in its claim to understand the sort of things as the familiarity of the individual case, as is questioned by Jardine (1998). “If an instance is simply duplicated in all respects over multiple cases, the duplicates add nothing new to our understanding” (Jardine, p. 43). The hermeneutic approach, on the other hand, does not position the final authority of concepts within the concepts and constructs themselves but “within the dialogically derived at agreement of people who consent to them” (Smith, 1994, p.119): meaning is arrived at relationally rather than

absolutely. Ultimately, through the hermeneutic tradition, “we thereby give voice to and show features of our lives ordinarily suppressed under the weight of the dominant economic, political, and pedagogical fundamentalisms of our times” (Smith, 1994, p. 123). In my research project, the challenge is to free myself from the allure of authoritative traditions of knowledge, and to engage in conversation with a number of people living with schizophrenia and diabetes in a journey of hermeneutic inquiry that gives rise to what Kvale (1996) describes as the simultaneous generation and interpretation of text and understanding.

My final challenge of interpretive hermeneutics relates to the task of returning to the ambiguous but familiar state of the question, before I learned to separate myself from the complexity of the subject matter of the lived experience with chronic illness. Much of my nursing practice has been concerned with the problems of chronic illness, for example, with issues of control, compliance, monitoring, screening, intervention, follow-up, and so on. If I am to use Burch’s (1986) statement, “questions and problems are not the same” (p. 6), I may be able to understand why certain methodological approaches, even though belonging to interpretive traditions, fail in certain applications or become problematic in themselves when applied to questions of events that evoke the “abiding sense of kinship and familiarity and embodied allure” (Jardine, 1998, p. 37). Gabriel Marcel (in Jardine) defines a genuine problem as one “subject to an appropriate technique by an exercise of which it is defined” (p. 6). I understand this to say that objective inquiry—that which is concerned with frequency and reoccurrence—is suitable for such things that are problematic. Therefore, if I am to explore the meaning of an instance that relates to the “experience of encountering diabetes for one living with schizophrenia”, I

must go back to the instance before I, as knowing subject, became severed from that sense of familiarity with the object that I no longer understood because I had become severed from its phenomenologic world. And it is from here that I begin, from that place of being “struck” by something.

I start here with my encounters of the participants’ stories of living with schizophrenia and diabetes or their concerns about their risk for developing diabetes. These writings are part of the development of the understanding that took place in the medium of language of what it means to be connected to the world of these two chronic conditions; “the hermeneutic instance on the articulation of the whole and the part” (Smith, 1994, p. 114). Opening in this way is an opening from inside out. As Smith notes, hermeneutically speaking, we find ourselves always in the middle of stories but good hermeneutical research shows an ability to read from inside out and from outside in. This writing is also a highlighting, which also means that it is not intended to be a reproduction of the original: “Translation, like all interpretation is a highlighting....The translator is often painfully aware of his inevitable distance from the original” (Gadamer, 1991, p. 386).

Joe Bell

I knew of Joe Bell during my few years working in the psychiatric in-patient unit, between 1997 to 2000. I did not have a close relationship with Joe and I do not recall that he was a patient that I worked directly with during the many casual hours that I had spent on the several open units or in the secure unit. I worked also as a community case manager in Schizophrenia Services following the in-patient experience and I ran across Joe once again. Joe was a resident in one of the group homes that my client was also

staying at and I would see Joe on occasion, smoking out on the patio with the other residents or engaged in polite conversation with one of the workers of the house. That is what I remember of Joe, that he was always polite, willing to do what was expected with no complaint or need to be asked or reminded of his responsibilities. Joe was almost too polite now that I reflect on my interactions with him. Almost ingratiating, like he was forever seeking forgiveness although there was a sense of pride there as well, with his tall grayish stature and deliberate tone of voice that seemed somehow higher in pitch than it should be. Joe did not present as a particularly relaxed or happy individual but he did seem content. Even though his movements were not rushed, but slow and deliberate like his words, Joe's facial expression was tight, as though there was a need to create a distance between the experiences and the emotions of his life. When he laughed, for instance, there was no smile. Joe may have had a greater plan but it was not evident, as though he was biding his time, waiting patiently. Always patient. Always a good patient.

Joe's interest in participating for this research project was clearly evident. He was the first one to contact me and from the moment we sat down in one of the common rooms that offered some privacy, to our goodbyes on the front sidewalk of the six-bed facility, Joe made me feel that it was I doing the favour for him and not the other way around. Entering into conversation was easy with Joe. He appeared honest in his comments and candid in revealing his struggles with alcoholism and his past manipulative behaviours that he is clearly not proud of but he does not wish to speak about the onset of his schizophrenia. Joe, in articulating the details he is willing to offer about his psychiatric condition, tells me that there was a mistake, "one thing way in the past...I made a bad mistake, which I don't want to get into..." (Joe: Transcript 1) for

which he believed everyone in the world was mad at him. He tells me that he is now able to walk down the street without the constant fear that everyone knows what he did or that they will punish him for this past mistake. Joe states that his fears are manageable now, “I’m on the right medications, now” (Joe: T1).

Joe told me that he has had many different types of medications and “shock treatments” during the early years of his mental illness. He adds that he was in and out of the psychiatric hospital, “I was like a rotating door” (Joe: T1) until 11 years ago when he stopped drinking after recovering from a severe hypoglycemic reaction that left him in a coma that he states lasted for 9 days. Joe was proud to say that he has been out of the psychiatric hospital for 11 years.

Everything changed for Joe 11 years ago after he had decided that he needed to stop drinking. “That’s the one [event] that woke me up the most” (Joe: T1). Joe tells me that he was in and out of hospital, “But I used to be in and out like a roller coaster, I’d go in 1 day, be in for 4 or 5, ‘Oh I’m o.k. now’, go out for 3 or 4 days, come back, want in again... I was like a rotating door”. Joe was also back and forth between Victoria and Vancouver, “until the social workers didn’t know who I was”. But all of that has changed when the alcohol stopped and the alcohol stopped when Joe came very close to death due to a severe hypoglycemic reaction. “I was in a coma for I think it was 9 days, and when I came out of it I was in Intensive care...just to see where I was at and finally, finally said, ‘That’s it, no more alcohol’” (Joe: T1).

Joe, now 60 years old, was diagnosed with diabetes the age of 32. Just as with his acceptance of his mental illness, Joe did not accept the diabetes initially and it was not until he quit the alcohol that he accepted having the diabetes. “Well, I accepted the fact

that I had diabetes about...10 years ago” (Joe: T1). Joe then corrects himself, “Well, it’ll be 10 years ago next Saturday”. It was the loss of control over his legs that gave Joe the realization that he needed to stop the drinking, “I’d be walking down the street and my legs would start to walk backwards....And that scared me and I said then, in early ‘95, I said maybe I’d better pack it in. And it was about a year later that I packed it in and said goodbye to the alcohol because it just screws up the insulin and stuff like that”.

The conversation moves to the years following as I question Joe about how he is managing his diabetes and schizophrenia now that he has accepted these two conditions, his paranoid schizophrenia and his diabetes. I want to ask him how it is possible to accept such things in life, the disabling condition of paranoid schizophrenia that interrupts life’s taken-for-granted hopes and dreams of relationships, work, family, and connecting with others. I think of his life on the street, in and out of hospitals and now in a group home for the past decade. The eternal poverty and dependence on substances like alcohol or cigarettes or the dependence on the caring professionals that have offered some relative degree of comfort; this is too much dependence for me and I think it should be too much for anyone, but what choice is there? I suppress the desire to ask, “Are you sure you have schizophrenia? Maybe the negative thoughts you have are not a sign that you are doing badly. Maybe they are there for a reason, for the reason you chose not to tell me. Maybe you made some bad choices and you need to get over that and get on with life.” But I cannot say any of these things. Perhaps this is my way of accepting only those things that I am willing or able to live with, and maybe this is how it is for Joe and all the others. How would one possibly accept the losses of what paranoid schizophrenia brings or the anticipated losses from the years of poorly controlled diabetes? I am struck by Joe’s

limited awareness into his conditions but what would this mean for him to know what he has lost? Perhaps he is able to live with these chronic conditions only because of his ability to have lost the insight, even though this puts him at greater risk for even more loss.

I ask Joe whether or not he is aware of complications related to his years of diabetes. I am interested in knowing what he understands about his risks for vascular and neurological complications and if he knows about the monitoring, examinations and lab work that his physicians should be arranging for him. Joe does have an annual eye exam and he knows that his cholesterol levels are good but he does not know his values. He tells me he has asked what these measures are but he is told, “it’s normal, whatever the amount is, I don’t know, but they tell said it’s normal, ‘don’t worry about it’” (Joe: T1). I am concerned that I might be causing Joe to worry about things he may have not been concerned with before our conversation as I press on. Joe recalls no urine testing for renal function but he describes coldness and numbness in his legs, “”They feel a bit numb today but the weather has some effect on me. She [one of Joe’s other physician’s] says I have what they call monopathy. Monopathy is a condition of the legs where you get cold, cold like you have diabetes and it gets cold up and your legs ache....It’s got nothing to do with diabetes, it’s just a condition of the legs” (Joe: T1). I want to correct him, to tell him that this is related to his diabetes and that it is unfortunately common and that it is progressive and that maybe it is not too late to change things now, but I resist. I ask Joe about his blood glucose testing, what his numbers are and when he tests. He tells me, “sometimes in the morning from 9 to 10 [mmol/L]. And sometimes 5 or 6 [mmol/L]...in the morning ...and in the evening, it can be 7, 8, or 9, sometimes 10...before supper.” Joe

checks only at the time of his twice daily insulin injections, not at bedtime or after meals, even on occasion. I understand what he is telling me and I have difficulty in not being the counselor, “concerned with the other as individuality—e.g., in a therapeutic conversation or the interrogation of a man accused of a crime—this is not really a situation in which two people are trying to come to an understanding” (Gadamer, 1991, p. 385). Joe knows that he has the lab test on occasion for assessing his average blood glucose level—the glycated hemoglobin (A1c)—but he does not know this value. He claims he has seen a dietitian before and believes, “They’ve got me on a pretty well-planned diet...I use Sugar-Twin in my coffee...and, ah, we’re not taking whole milk, we’re drinking half-and-half—half regular milk and half skim milk—in a jug. And ah, you know, I, I, I’ve never gone hungry here. I’m not hungry here” (Joe). I understand here what he is telling me. That *not* being hungry is significant. That being out of hospital is meaningful. That not having a ‘black-out’ from low blood sugars is good.

Joe says his conditions are manageable now and it is clear that it is his physician of 11 years who he trusts, “The only time I go into hospital is when my doctor says so. Not my nurse, not my lawyers, n-nobody else” (Joe: T1). Joe depends on his doctors for medication adjustments and he has come to a place in living with his conditions that he will do what he is told. He has learned from mistakes of the past that he is not able to manage his schizophrenia or his diabetes on his own. Joe has given himself to the higher powers, not only of psychiatry and endocrinology but to Jesus, “in A.A. they tell you to pick a higher power and my higher power was Jesus and I started to pray and, ah, little bits here and there that I wouldn’t go through that and end up in hospital again...It’s my own Christian belief, that’s my higher power” (Joe: T1). He acknowledges his own role

in his ability to have made a difference, “I remember it was my own attitude too” (Joe) in speaking about when he was first told of his diagnosis of schizophrenia. I find that I want to agree with Joe in believing that he is able to manage his conditions more independently and I am aware that I find it difficult again to understand his dependence, but it is not the intent of this conversation that I understand him. “ It belongs to every true conversation that each person opens himself to the other, truly accepts his point of view as valid and transposes himself into the other to such an extent that he understands not the particular individual but what he says” (Gadamer, 1991, p. 385).

In our coming to an understanding about this subject matter, I have learned what works and what does not for Joe in his life with diabetes and schizophrenia. He has faith and trust in particular health care providers but these do not include those at the Diabetes Education Centre. At 60 years of age, Joe is now looking forward to increasing his independence by moving into a satellite apartment of his current facility. There he will live without the immediate supports of the group home but he will hopefully continue to manage his diabetes as he has for the past years, “Give me 5 minutes and I’ll have a smoke then a coffee and then we’ll do it...That’s it. And then I do it again this evening. I do my insulin at ten to 8:00 and give myself like 10 units of a cloudy. Nothing to it...It takes longer to tie my shoes...I do it automatic” (Joe: T1).

Al

Al was aware of this research from my meeting with Joe. Al lives at the same 6-bed group home and on the day of my conversation with Joe, Al asked me when I would meet with him. After speaking to Al about the nature of this research and hearing that he

had a concern about his diabetes risk, I left him with a copy of the consent form and returned in two week's time for our conversation on this subject.

I was apprehensive about meeting with Al because of what I knew of him from my previous interactions as his case manager. Our relationship had not been difficult but I was unable to recall a conversation longer than one minute. I thought of Jardine's (1998) chapter on "*The Fecundity of the Individual Case*": *Considerations of the Pedagogic Heart of Interpretive Work* and I doubted that there could be sufficient content from our conversation for an individual case with Al. But as I re-read Jardine and reflected again on my conversations with Al and with some of the others who participated in this project, it occurred to me that what was already familiar was precisely this poverty of expression and how it relates to diabetes that I did not yet fully understand. "Inquiry begins by being 'struck' by something, being 'taken' with it" (Jardine, p. 40) and in this particular case, the apparent absence of significance or understanding of what it means to live with the cognitive challenges of schizophrenia and the cognitive demands of diabetes. As I write of my prejudice, or pre-conception, I am aware that it is not only the understanding that I am seeking in what is said, but in what is *not said*.

Al, as I expected, was very superficial in his description of his mental illness but he did admit that he hears voices when falling asleep and that he needs medications to stay well, "if I don't take the medication, I get quite angry and out of control" (Al: Transcript 2). Al now tells me he is very happy with his current living arrangement in the psychiatric group home, "Very lucky. There's always food in the fridge, (pause) clothing allowance, (pause) and food, (pause) and shelter and (pause) very lucky to be here." (Al:

T2). These things are important to everyone, but it is not common to hear someone express appreciation for these basic things: food, clothing, shelter.

Al is 46 years old, but he has been living with schizophrenia since he was 21. He is on a medication regime for a schizo-affective disorder, Risperidone, Zyprexa, and valproic acid, and while he had gained a considerable amount of weight in the past he is not aware of any side effects from these medications. Al has managed to lose the 40 pounds that he has gained but he is initially reluctant to tell me how he achieved this, “Oh that’s a story (laughs). Too long to tell” (Al: T2). I ask him if this required considerable effort and he responds, “Ah, I just didn’t have enough mo-, money for food. I was going to restaurants and buying a lot of cigarettes” (Al).

Al expressed sufficient insight to know that he had not been able to remember to take medications and he believed this would be the biggest challenge if he were to develop diabetes. He is aware that he is at risk for this condition, “just a-a faulty gene for diabetes, you know....On my mom’s side...My Mom’s side has pretty well had it [diabetes]” (Al: T2). Al is not concerned about whether he would need pills or insulin or even need to test his blood glucose levels, “Well, I’m not too crazy about any of that. Like every day you have to think about your insulin and....but if I have to stay alive, I’ll take them I guess” (Al: T2). Al surprises me. He is not forthcoming with his anticipations of what life would be like if he were to develop diabetes but he does know the basic of what is required in managing this condition. He knows that medications for diabetes are often required as is regular exercise and dietary changes, “Yeah, oh diet, yeah for sure. Yeah. Not so much sugar, or no sugar, I guess. Just natural fruit sugar, I guess” (Al: T2).

I ask Al if he knows of anything else in his diet that might contribute to elevated blood glucose levels and he surprises me again with his reply, “Maybe...starchy foods?”

Al has been told that diabetes is inevitable, “I keep hearing that I’m supposed to get it sooner or later” and he tells me that he also knows that people with mental illness are even at a higher risk for developing diabetes. Al is being screened for elevated blood glucose levels every six months and he has been told that his cholesterol levels are high although he is not on medications for this metabolic issue. Al’s main concern about developing diabetes and managing this condition is his fear that he would be unable to remember to take medications as prescribed, “...I’m one to forget. That’s why, that’s why I’m scared just sort of remembering to take, ah, the medication” (Al; T2).

I ask Al if he were to be diagnosed with diabetes, would he be interested in coming to the Diabetes Education Centre to learn more about managing this condition. “Yeah, yeah, that would be good...’cause I don’t eat quite healthy, like balanced meals and all that so...” (Al:T2). He is even able to tell me what he would like to receive in terms of education: “I’d like to know how many calories I’m supposed to eat” (Al: T2). At least he is open, I think to myself. There is possibility here despite the limitations of schizophrenia or whatever else Al is unable to control. Perhaps he is at a place in his awareness of the requirements of diabetes management because of having so many family members with this disease. Perhaps Al is almost ready to make certain lifestyle changes once he finally receives the diagnosis of diabetes. All he needs is to be pointed in the right direction, and reminders along the way.

Al reveals to me that he has also two brothers with diabetes and that there are two children of his oldest brother also with diabetes. So, assuming he must realize the

seriousness of his eminent risk, I ask what he is doing in terms of getting regular exercise to prevent his risk for diabetes and he responds with, “Not too much. Not enough...No, I’m basically a couch potato (laughs)” (Al: T2). I notice that Al laughs at the serious things. Even when he told me that he has schizophrenia he draws out the ‘a’ in a playful way, “But I have schizophreniaaaaa!” (Al: T2) as to say this doesn’t really matter. More likely, it matters more than he can say but what else is he to do than laugh. Al at least can laugh at his difficulties, but of course when he is unwell, his inappropriate laughter quickly blends into anger and he loses control. Control. It occurs to me now that this is what Al and all of the others have lost: control. This is also what I understand is essential in managing diabetes: controlling blood glucose levels, controlling diet, controlling weight, controlling blood pressure, and controlling cholesterol levels; all for controlling the risks for heart disease, stroke, peripheral vascular disease, peripheral and autonomic neuropathy, kidney disease, blindness, and amputation. Al is not making any changes until he is diagnosed. At the end of our conversation he asks me for a ride to the store to buy cigarettes that is three blocks away. I oblige him; after all, I am heading the same way.

Greg

Greg is one of the participants that I know through both my experience in working in mental health and in diabetes services. He is very interesting to me and to this research because he remains a very challenging client in that his diabetes is so poorly controlled despite regular visits to the Diabetes Education Centre. Greg has attended appointments with one of his mental health support workers at the DEC every four to six weeks for the past few years to see an endocrinologist, a nurse and a dietician. At the time of this

meeting Greg was living in one of several buildings on the grounds of a tertiary care facility. His building is much like the group home environment like Al and Joe reside although where Greg lives, there is greater possibility in moving a resident to a more secure or supportive environment should he require more control to keep him from harming himself or others.

I meet with Greg in his room at what is called the “Old House”, where apparently the greatest degree of independence is offered within this psychiatric facility. Greg is initially reluctant to meet in his room, but due to the intrusiveness of another resident while we sit in the common area, he decides it is better that we relocate to his own room. On entering I see why he had been reluctant that I come here and I think that he has had too much independence. His 1-bedroom apartment, complete with kitchen, looks as bad as any I have seen during my experience as a case manager when visiting clients in their homes. I am unable to place my recorder or note pad on the coffee table due to the layers of coffee stains and rolling tobacco residue. I need to reposition his refrigerator to stop the noise resonating from the expansion coils that have been pressed against the back wall. I act as though I am not surprised by any of the disarray so as to not cause Greg to feel defensive but he appears as neutral as I do within the chaos. I think to myself, he must know how it looks from my perspective, after all, he has been to the clinic and knows what my environment looks like. Sitting in one of his well-worn upholstered arm chairs, I balance my recorder on my knee and begin our conversation.

Greg, at 29 years of age, has been living with schizophrenia for 12 years and type 1 diabetes for the past 4 years. As I begin the conversation with Greg I am struck with the level of his misunderstanding about his diabetes – there are threads of reality and

understanding – not a common or shared agreement of what is required of someone living with diabetes to reduce health risks, nor do I attempt to arrive at this. The threads of Greg’s insights are tenuous and severed by the next articulation. I see that I am not helping to correct him but at times I think I am even reinforcing his misunderstanding – perhaps this is my way of believing that I am helping – to not threaten or contradict – but to allow him to continue to tell me about his life with diabetes and schizophrenia. Perhaps this is Greg’s intentional lack of awareness as a coping mechanism that is consistent with my preunderstanding of people living with schizophrenia. I wonder who is being helped here.

Greg was diagnosed with type 1 diabetes in 2002 and did some work on a farm and later moved back to the city for other work. Things got worse he says, “not necessarily voices but, you know, I could see the devil in everybody and the fucking light was the wrong colour, right?” (Greg: Transcript 3). Greg admits that there are certain things about looking after his diabetes that he does not like, “Doing the finger prick and the blood sugar taking” and he even admits that he misses his insulin, “once in a while, I slip and I kinda go but it’s not a habit” (Greg: T3). This may not be quite a habit but for Greg I know it is all too common. I would be interested in pulling his hospital records counting the frequency of presentations to the emergency department for diabetic ketoacidosis. I wonder if I could count them on two hands.

When asking Greg to tell me about his mental illness, he, like Al and Joe, is brief in his description of his symptoms of schizophrenia, “And then it just gradually just crept up and went away and that’s it. I take medications now and that helps me through the day and sometimes through the night.” (Greg: T3) but later in our conversation more comes

out, “it was basically about anger and how to deal with it....I had bizarre thoughts, yeah, but those are a thing of the past” (Greg: T3). I know that the anger is not a thing of the past for others who live or work with Greg. His psychiatric support workers have stated that they are only able to encourage Greg to do things around his diabetes to a certain limit. If they expect that he checks and records his blood glucose levels more than once weekly, their relationship with him breaks down and they lose contact.

Greg tells me he is, “basically here for detox” (Greg: T3) to help him stay off cocaine and other street drugs although he tells me he occasionally meets up with other residents to smoke marijuana. He is hoping to live another 10 years but when I question this, whether he would be really happy with another 10 years, he replies, “Well at least another 25 years working, so hey I don’t want to always fucking live off the government” (Greg: T3). Greg hopes to be working in about 2 or 3 years time, after another year of school to upgrade and then to find work in a logging camp or on an oil rig, “big money on one of those, man. They, their crew, they’ve got the budget for the broccoli and cheese” (Greg: T3). Greg knows that he has been living with very high blood glucose levels, “Way up there” (Greg: T3) and states that he is happy and feels better with readings in the 10-15 mmol/L range, but this is still two to three times higher than normal. How many times has he heard that these high blood glucose levels will give him health problems, such as the infections he has already experienced in his legs, or has he not heard this often enough? Greg’s response to the question about where he likes to keep his blood glucose level at does not come as a surprise really. People who have lived with relative hyperglycemia, in the levels similar to Greg’s, do not feel well with the normal levels of 4-6 mmol/L, at least not immediately. They actually complain of symptoms of

hypoglycaemia related to the adrenergic response that often includes an increased heart rate, anxiety, irritability, and tremor. I expect that Greg is motivated to keep his blood glucose levels high because of the unpleasant symptoms that from the hypoglycaemic-like reactions.

I turn the conversation to his contact with the DEC, wondering what he perceives these regular visits have been for. Greg replies: “I like it when they care and when love is there but when it’s not, when you’re dealing with stressed-out people like that, it, it makes it all much harder. But they’re loving and caring, they help you, they hold your hand, they pick you up off your feet, and stuff like that...” (Greg: T3). I have sat in on many of Greg’s appointments at the DEC and I know that he is not challenged or criticised for his out-of-control blood glucose levels or for his unwillingness to show any evidence of his blood glucose testing. Maybe we know what Greg is capable of or willing to do, or maybe there is much more here than I realize but I will get into this later.

I press Greg to know whether or not there is anything that he needs to do because of his diabetes that is important to do to prevent health problems. Greg replies, “I don’t know, just a balanced lifestyle”. *Live a balanced lifestyle*, but what does he mean and what do we mean when we use this phrase? He gives me an example: “Well, breakfast would be English muffins or cereal. Coffee. I’ll have a half pot of coffee. It’s about two of these cups [pointing to a large cup sitting on the table beside him] and juice and hash browns, like potato patties. Like you can buy 20 for like \$3.50” (Greg: T3). Greg describes his other meals and it occurs to me what he means by *a balanced lifestyle*: Greg means that he is not going hungry, he means that he can come up with a few things at meals and feel well enough to have some freedom to hang out with his friends, and

maybe upgrade his school and get a job one day, way up in a logging camp or on an oil rig. These sorts of things were also important to Al and Joe: not being hungry, having a place to live, and looking forward to more independence.

I return to my questioning, “Like conversation, interpretation is a circle closed by the dialectic of question and answer” (Gadamer, 1991, p. 389).

Researcher: “But any particular health problems you think you’re, you have to worry about?”

Greg: ‘No’

Researcher: “O.k. How about from those people around you...Have any of them talked to you about things they seem to be more concerned about than you do?”

Greg: “Just take care of my feet and my eyes...Everything wears out in time, even metal. It turns to rust right?”

Greg tells me, “He’s [the endocrinologist] helping save my life, right? I want to live for at least another 10 years”, and when I ask him later about how important the nurses have been to him, Greg replies, “If they weren’t there, I don’t think I’d be living right now. You know, I’d be like way in whatever you call it, debt, like, really far fucking gone from reality...” (Greg: T3). What does Greg understand when he states that his life has been saved? This seems to contradict what he has stated earlier about only wanting to live for another 10 years. “They have saved my life” (Greg: T3). Trying to understand what Greg understands. I am uncomfortable with his lack of the basic knowledge of diabetes and what is required to manage this condition. We who have seen him at the Diabetes Education Centre have told him how important it is for him to manage his diabetes. Manage, required, knowledge, and control; these are terms that do not fit easily

into Greg's life. They are aspects of functioning that are beyond him and aspects that belong to those of another world. A world that has developed the language that has become my understanding of diabetes. I know Greg has been to the education centre for meetings with the endocrinologist, nurses, and dietitians. What has this system done to help him? He seems to have gained so little.

For Greg, being able to prepare his own meal is a significant achievement. He is proud to be meeting with me to discuss his ability to look after his own needs. I am unable to say to him that he is harming himself—his vascular system—significantly adding to his risk for a heart attack, stroke, or perhaps vision loss. I am not saying what I know should be said—what is said to others who do not have schizophrenia. Others hear that there are ways to reduce the intake of saturated fats and refined carbohydrates, not to eat “Tater Gems” for breakfast or “Taco Bites” for dinner. Is this a preunderstanding that Greg is challenging—that I have understood that I cannot help people like Greg to the extent that I am able to help others? Am I able to abandon him because he does not see it as so?

There is more in what is not spoken than in what is. The fundamental meaning of the Text with Greg: *You will receive that for which you seek. I will only help you with that for which you ask.* Greg has no particular health problems, “Take care of my feet, hope to live 10 more years...no 25 maybe” (Greg: T3). He believes that there is a responsibility among professionals to help society and kids with diabetes. Greg recites something he has seen on the television about stem cell transplantation and a woman who has benefitted from this technology who is now off insulin for one year. “So I've got something to look forward to. I know, I know that someone is going to figure something

out next, it's just a matter of time before it shows itself" (Greg: T3). He knows but doesn't know. "Oh, it would be impossible" (Greg: T3) to look after his diabetes while on cocaine. That he knows. Some insight, "Short time escape but...like the next day I would feel it [the pain]". "If they [the diabetes care providers] weren't there, I don't think I'd be living right now." Greg knows his condition is serious, that he needs help to stay well but his knowledge about this condition is inconsistent.

John

John's first psychotic break occurred when he was in university and was on a work term that he was unable to complete due to the acute onset of his psychotic symptoms. He describes this later in our conversation as, "it's a fear, it's also, um, I'm afraid of my own thoughts, I'm afraid of what my mind is telling me..." (John: Transcript 4). John is keenly aware of his difficulty with maintaining even the most basic activities such as getting out of his apartment to shop for food, keeping his place tidy, meeting friends, and being physically active on a regular basis. John describes himself as a "social embarrassment," (John: T3) a terms he refers to repeatedly during our conversation and the reason for why he did not want to meet at his own apartment for this conversation.

John is unusually articulate in speaking of his life with schizophrenia and of his concerns about how he would manage living with diabetes, in the event this does occur. Coming to an understanding on the subject matter with John about the encounter of these two chronic conditions occurs easily, evident in his words, "Um, my lifestyle is, is quite, um, puts me at more of a risk because I don't partake in things that I think would help sort of prevent me from getting diabetes, like exercise, diet and that kind of thing" (John: T4). His words on this subject speak for all the others with, "Like sometimes I feel that,

um, feel that I, I just don't really care to do the things that I need to do to keep healthy" (John: T4). In John's opening response to my question about the subject of this study, he articulates his other risk factors for diabetes: "first of all, I, um, am pre-disposed to...I am diagnosed as a schizophrenic, um, and I understand that there is a potential for getting diabetes, there is a possible link between the two... on my Dad's side, um there is a history of diabetes" (John: T4).

John has been hospitalized on one other occasion since he was diagnosed about six years ago although he says there has been, "ups and downs and it is very, um, topsy-turvy you might say" (John: T4). I met him as his case manager in the year 2000, after his first discharge from the acute care bed in the psychiatric hospital. As I have written earlier, he was involved in a work term through his university degree program at the time of his first psychotic break. He has been unable to return to this but he tells me that over the past six years he has been involved in odd jobs—volunteer and paid work—that has provided him some structure and with a sense of productivity. His "cycling of ups and downs" is what he suspects is the reason for why he is unable to maintain the basic routines such as regular exercise, "I still struggle with my routine things because, um, like trying to maintain a regular ah exercise routine is, um, somewhat challenging. Um, I suspect it has something to do with...um this sort of cycling of ups and downs" (John: T4).

John tells me more about his better days, about his periods of success with maintaining regular physical activity. "What drives me to continue on with when I'm doing well is the, the motivation and the sense of purpose and meaning in, um, in participating in the, the things that sort of give me a sense of, you know, reason to reason

to do them” (John: T4). When doing well, the motivation and sense of purpose and meaning from participation give him the reason to do them: wellness supports wellness. It is like a circle that reinforces itself. I consider then that the opposite is also true: illness reinforces illness. Perhaps this is why the participants of this study do not easily elaborate on their experiences with their mental illness. Maybe they have learned that in believing you are ill, you will be. Perhaps what I have understood as denial of the impact of their mental illness on their day-to-day lives is indeed a coping mechanism. How much awareness can you have about things you cannot change?

John will not get a pass for the recreation centre for more than a month at a time. Even the motivation from all the goodness is not enough to keep him going. “I don’t want to go out and buy a year-long pass. I just want to get a year—or month, pass and see how that works and then when that expires then it’s just like well that didn’t really work. I don’t really want to do that anymore” (John: T4). John struggles to find an activity that stays meaningful, “that’s, that’s a very key point, I think, is, is, is having something that has meaning to me, or to anybody, um to, to, to find that interest in the, in the activity that you need to do to keep well is important, right?” (John: T4). There is something that he needs to find to help him stick with the activities. “I just, you know there is something that has to happen to give you that, to give me my motivation to...to stick with it” (John: T4). John speaks of the exercise group through the Day Hospital and how there was “not high pressure, an obligation, you know, a responsibility to be a part of the group, to keep the group going”. He speaks of the instructor who he liked, the social skills that he knew were somewhat lacking in his life, and knowing that he is doing well because he is enjoying being with people and participating in the activities. John tells me that he

wanted to continue with the exercise group but he adds, “unfortunately I can’t right now” and I do not ask him why.

I do ask John if he is able to talk about when things are not going so well. I tell him that I know this might be hard to explain but he says, “Yeah, I can describe that” (John:T4). John begins by telling me that isolation and the feeling of being trapped in his apartment are possible residual symptoms of his schizophrenia and that he feels that he cannot go out because at times his symptoms are so acute that he is having thoughts that someone out there is going to harm him, or he has paranoid thoughts of someone out there thinking he is a weird person or that he might be a threat. John says that when he feels he is a threat to others this keeps him from partaking in daily activities and he knows that it is his thoughts that are trapping him in his own apartment, “keeping me, um, undercover and keeping me away from going out in the community and being involved with things” (John: T4). He admits he has difficulties with maintaining a comfortable and organized apartment, which makes him suspect that others will know he has “these problems” and that they will therefore think less of him. “I mean, there’s the lifestyle things and there’s also this sort of thing that you need to take care of that we all, we are responsible for... And um, you know, when I’m not doing those sorts of things, I become ah, you might say, socially embarrassed...” (John: T4).

How much awareness is it possible to have, of the things you cannot change? I arrived at this point in my research with the foreknowledge that this population generally lacked insight—into their illness or wellness—and were therefore more vulnerable because of this. John has challenged my view on this although the others before him have opened the door on this knowledge that I brought into the conversations. John has shown

me that he is vulnerable *because* of his insight into his illness. The process of moving from insight into action is a complex one and my conversation with John shows me that having insight does not necessarily facilitate this process. The questions and answers of our conversation reveal to me a sense of *being struck by something familiar*: inaction *despite* awareness.

John continues to speak about the barriers within his own mind, “Those barriers are inside of me, they’re in my mind, that I don’t want, um, to share” (John: T4). But he has learned to get out of his own head—when having the troubled thoughts, intrusive thoughts—to utilize one of the resources that helped, the Need Crisis line.

John is striving to learn how to better manage his schizophrenia and he is able to articulate with insight the lessons he has learned through the periods of wellness that have been punctuated by his psychotic breaks. He has learned to trust the people of his support network, whether this is his parents, his case manager or the person on the other end of the phone when he calls the Need Crisis Line. John knows some of the essentials of healthy eating and physical activity that are helpful in preventing or slowing the progression of diabetes. Although John is not working, he states, “I have enough to deal with right now with the schizophrenia...I have a pretty busy schedule with taking – making sure that I’m going to day hospital and make sure I make all my appointments” (John: T4). His concern is that diabetes will be just one more worry, and worries he has enough of, without diabetes, “I get down enough because um, I’m predisposed to schizophrenia and a small, to a small degree, social anxiety. Um, so I’m, I’m dealing with those already and that that’s just, diabetes that’s just one more worry” (John: T4).

Randy

I have no previous knowledge of Randy other than a brief conversation with one of his nurses on the schizophrenia unit of the Eric Martin Pavilion in Victoria. His nurse tells me that he has been in hospital for several months and he has expressed interest in participating in this research due to his significant weight gain from his medications. I meet with Randy in one of the interview rooms on the fourth floor of the psychiatric hospital. He tells a bit about himself: "I'm 22 years old. I was born at Vic General Hospital. I've moved a lot in my life and I have been in the hospital for the last 6 months and supposed to go to a group home and that's about it" (Randy: Transcript 5).

Randy is not elaborate in his descriptions of his symptoms of his diagnosis of schizophrenia but I am coming to expect this. Like Al, Joe and John, he wants and needs to be well: "I have to really trust the idea that things are gonna work out, even though I don't feel good right now" (Randy: T5). In his response to my questions about the symptoms of his mental illness, he offers initially, "Ah, it just feels like sometimes, like I know that I'll come out the other end and everything will be o.k." (Randy: T5) but later in our conversation he tries, "it's like this little thingy in the back of my head and it becomes this big thingy if I have to do something serious" (Randy: T5). Randy tells me that he was diagnosed with schizophrenia at the age of 18 and adds that he has been told by his psychologist that he also has narcissistic personality disorder.

At the time of our meeting, Randy has been in hospital for six months and he has gained 60 pounds, stating, "The old paunch on me now. I haven't been putting on weight for the past month. I'm steady at like 206, 207, something like that" (Randy: T5). His weight gain had become a type of insurance against starvation, should he be discharged

from hospital and find himself unable to secure adequate food during the three months that he estimates he would likely be able manage independently, before needing to be dragged back into hospital. He has learned something of the course of his illness: “I’d be o.k. for a few months. But I’d relapse and I’d break down, probably end up in the hospital again” (Randy: T5).

When I had initially met with Randy to discuss the purpose of my research he had revealed to me that his significant amount of weight that he had gained since hospitalization had been a concern and that he knew that he was at greater risk for diabetes because of this. Randy’s concern at the time of this conversation however was not on his weight but on where he will be going after discharge from the acute care bed in the psychiatric hospital, “they don’t even give me that I’m going somewhere. They just make like it’s an endless abyss of like being in the hospital and like always getting pills slammed down my throat” (Randy T5). I wonder if his change of focus has to do with what John had expressed to me about his difficulty with maintaining a routine: that life with schizophrenia simply gets in the way. In Randy’s case his problems seem to be more of the limitations and expectations of his environment rather than the limitations within his own mind, but later in the conversation this too becomes evident.

Randy acknowledges that his marijuana use is problematic but it is not clear to me that this is something he plans on quitting. He believes that his marijuana use is the reason that he is being told that he is unable to live on his own, “When I’m out on my own, that’s the first thing I go for, right? So they’re just telling me like I’m not allowed to live on my own anymore” (Randy: T5). He shows what I call insight into the consequences of his “pot” use: “I display symptoms when I smoke pot.... when I get high,

you start thinking high thoughts instead of straight thoughts and then you get caught up in something stupid that you're thinking of, you know?... I'm paranoid enough without pot (laughs)" (Randy: T5). But Randy admits that smoking marijuana does help him feel better, "Cause that's, the first 10 minutes is just fun, like you just feel like kinda stunned or faced, right? And then, after that, it's like, harder" (Randy: T5). I understand that 10 minutes of fun would be very appealing when living with schizophrenia and that trying to hold the bigger picture in view—of how this or that might affect the course of events—would only increase my understanding of what I have lost.

I explore with Randy the significance of his mental illness on things like his income, his ability to work, cooking, and planning meals: "Um, I get \$90 a month. My Dad wants me to work so bad but I can't hold down a job. I'm crazy.... it can happen all of a sudden. I can be just fine for all day and then all of a sudden, for no reason, I just go schizo-affective on something, you know? And it just sets me off.... Because I do have a mental illness and it does make it hard for me to work, you know?... I know how to cook; it's just that I choose not to. I get the food that's easy to eat and something I'll actually eat instead of a bunch of apples that'll just go bad, I get food I'll eat" (Randy: T5).

Researcher: "What kind of stuff would that be?"

Randy: "Pizza Pops, ice cream, Skittles, apple fritters, juice, pop—just basically young guy's diet, you know? Just like total junk food"

More insight from Randy; he knows that he is not making the healthy choice but he is making the easy choice because he has enough harder choices in his life: "Look out for number one 'cause nobody else is. I got nobody on my team, like people to back me up, nobody wants anything for me except to go to a group home and be a quiet, good

little boy. I'm not like that. I don't like having my life taken away from me like that.... I gotta work out some of the things that I gotta do with my life, on my own" (Randy: T5).

Laurie

Laurie is one of the three participants in this study who is unknown to me and I wonder what significance this may have on coming to an understanding on the subject matter. Perhaps it makes no difference at all as it is not the intent of this study to get inside the other person to relive his or her experiences, "that he understands not the particular individual but what he says" (Gadamer, 1991, p. 385). This shift in view from understanding the individual to understanding the subject matter continues to be challenging for me as I enter into conversations with the participants but perhaps the relative anonymity between Laurie, Randy and Matthew and myself serves to focus my attention to the text that emerges from our coming together, for example, on the question of, "What is the unmanageability of *life* for people living with schizophrenia?"

I meet with Laurie in an interview room through the Victoria Mental Health Centre. She has her own apartment but chooses to meet at the mental health centre. Laurie is a client of a case manager who is well known to me and as I reflect on this, I realize that all participants for this study have either known me from when I worked in psychiatry or were referred to me through their health care providers who I knew well.

I ask Laurie to begin by telling me what she can about her experience with her mental illness and she responds with the dates of her psychotic breaks, beginning at the age of 30, another at 32 and 33, and the most recent event three years ago at the age of 38. I ask again to give me some idea of what life was like for her at these times, perhaps an unnecessary question. "You want more specifics?" (Laurie: Transcript 6) and she tells

me that her first psychotic break occurred at the time her parents were dying and her relationship with her husband was breaking up. Laurie then tells me that she was working as a nurse but required a 2-week hospitalization due to the severity of her symptoms. She was started on Haldol, one of the so called “typical” or “first generation” antipsychotic medications that was commonly associated with side effects related to the movement disorders of the extrapyramidal system, causing tremors, restlessness or tardive dyskinesia. What was not associated with the earlier antipsychotic medications, except for probably chlorpromazine, was weight gain. Laurie returned to work after her first episode with psychosis but looking back she realizes she was not as well as she should have been. Due to the side effects from the Haldol, her physician tapered her off the medication and within a couple of years of her first hospitalization she was readmitted to the psychiatric facility, this time for a three-week stay. She was started on a new antipsychotic medication, with new side effects.

Laurie: “Um, they...what’s the drug that’s really known for weight gain?” (T6).

Researcher: “Olanzapine”.

Laurie: “Olanzapine, yes. So I went on Olanzapine the second time” (T:6).

Researcher: “Did you gain a lot of weight?”

Laurie: “Yeah, I gained a lot of weight. I gained a lot of weight with the Olanzapine and then I’m on the Risperidol Consta now... I’ve gained about 100 pounds with the Olanzapine and I was able to get some of it off, and then from the first start on Consta, I’ve gained 75 pounds” (T:6).

Laurie experienced changes in her appetite following the medication change, becoming noticeably hungrier and craved carbohydrates. Her depressive symptoms left her with wanting only to sleep and eat. Work was no longer a part of her life and this added to her depressive condition. She recalls being immediately concerned about her physical health but felt too helpless to do anything about it. At the time of our meeting, Laurie weighed 270 pounds, nearly double her 140 pounds that used to be her top weight. I would call that a catastrophic consequence, not a side effect. So I ask her what must sound like a stupid question: “What’s that been like?”

Laurie responds by telling me she feels really depressed and discouraged, “the number is so large, you know, to get it under control” (Laurie: T6). She had made some progress with weight loss after her first 100 pound weight gain, managing to lose 40 pounds through cutting out snacks, eating a lower fat diet, and walking more, but this was during a period when she was feeling better. With medications changes and the return of depressive symptoms, she gained the 40 pounds back plus another 35. We talk about how this weight gain adds to depressive symptoms, how this adds to the sense of a loss of control and how this increases her risk for diabetes, a condition her father had but she thinks may have been steroid-induced as he developed the diabetes during his treatment for the leukemia.

It is at this point in our conversation Laurie tells me the type of nursing she was doing at the time of her illness:

Researcher: “What type of nursing did you do?”

Laurie: “Psychiatric” (T:6).

I laugh, but not because it is humorous, but because of the irony, the sadness, the unfairness, and the tragedy and because I know that she must have seen others experience something similar. “Yeah, I did” Laurie states in reply to this when I offer the question. We know it does not make it any easier to know the possibilities, in fact Laurie says it was harder because she identified with the staff and not the patients and when being a patient in hospital these relationships changed too.

The conversation returns to her psychotropic medications, about her periods of “non-compliance” with the pills due to her lack of insight into her illness or to the benefits of the medications, or because she was too ill to understand. So she is now on the long-acting psychotropic medication given intramuscularly and Laurie believes the current medication regime of the long-acting antipsychotic, the antidepressant, and the mood stabilizer are working: “It seems like the best result that I’ve had of anything” (Laurie: T6).

Laurie knows of no plans to review her medications because of the weight gain, “It’s sort of taken a backseat because we tried so many medications to get to this point of wellness that I don’t think my doctor is willing to make any changes” (Laurie: T6). She says she is fine with the decision, “Um, I am because I was so ill, I just don’t want to go back there” (Laurie). Psychiatric stability trumps physical health. So now she focuses on what she can do to with her “lifestyle” to reduce some of her weight.

I ask Laurie what her most recent strategies for weight loss have been. She has tried the walking group like the one John found so helpful, but for Laurie it did not work, “Um, I gave the day hospital a shot. It bored me to tears. I just walked around a track” (Laurie: T6). She has a membership to Curves, a drop-in cardio and resistance fitness

eat” (Laurie: T6). Laurie has not seen a dietician during any of her admissions to hospital but since connecting with me for this research a referral to the DEC is made by her case manager. Laurie is hoping that her appointment with one of the dieticians will provide her with effective strategies for weight loss.

Matthew

I received the inquiry from Mathew through his case manager in the schizophrenia services and I was able to reach him by phone to arrange a time for me to drop off a copy of the consent form. The following week we meet in his apartment. It is late June, with the recruitment and interview process now about 6 months in duration and I decide that he will be my last participant. Time does play a role in this decision to close the recruitment for this study but more importantly I believe that there is sufficient complexity and multiplicity from the conversations to inform this subject on the encounter of schizophrenia and diabetes.

Matthew’s subsidised 1-bedroom apartment is surprisingly stark. He has no real dining table or living room furniture but there are two folding chairs, a TV tray table, a television, and a stationary exercise bike. On the walls are various drawings and paintings that he tells me later are his own works. We sit in the folding chairs across from each other and begin our conversation. Matthew looks at me throughout the conversation with a staring expression, giving away little else in non-verbal cues. He appears neither comfortable nor particularly anxious but his verbal responses are abrupt.

Mathew’s description of his psychotic symptoms that occurred at the time of his diagnosis is very brief, “Oh, um, I was wandering around without shoes on....That’s it” (Mathew: Transcript: 7). Matthew was diagnosed, from what I am able to discern, around

1985. He has been living with schizophrenia for the past 22 years and has required hospitalization, “once or twice” (Matthew: T7) over the years with his last admission occurring about 5 years ago. He claims that he is independent and that he has been doing well, not requiring any supports, “I’m pretty independent” (Matthew: T7). I am not able to determine if Matthew has active or residual symptoms of schizophrenia that would add to his risk for diabetes or interfere with his ability to manage this condition, so our conversation moves on. Matthew does not attend the day programs through the psychiatric hospital, “I have my own thing that I do, like going to Networks” (Matthew: T7). I learn that he is receiving assistance with job finding through this community organization.

The conversation turns to his medications. He has received a change in the type of antipsychotic medication 3 ½ years ago. He is now on Clozapine and he agrees that he has been better than when on the Risperidal, but he does not elaborate. He has no complaints of medication side effects but he does admit to having a concern about his weight. Mathew declines to tell me how much he weighs now, how much he has gained, or how he would like to lose, “Um, I’d rather not say” (Matthew: T7). But he would like to lose some weight and I ask whether this has been particularly challenging, “No, no, I’ve been doing all right...hoping to lose more” (Matthew). I ask him about his strategies for success: “Ah, different eating habits and exercise” (Matthew). With more prompting, he replies, “Oh I just cut back on calories, calorie foods, you know, like pasta, and rice and stuff like that.” He has the basic idea, I think to myself, and I move on to the exercise part of things.

Matthew states that he is “on and off” with the exercise bike—his admitted favourite form of physical activity—and quantifies the number of times he uses this in a week as, “zero and one I guess...not as often as I would like to” (Matthew: T7). Matthew is looking for work, and he tells me that this is one reason the he is unable to use his stationary bike more often but he admits later in our conversation that motivation is a challenge for him, “Ya, I have a problem with motivation, but I try to just be...consistent” (Matthew: T7).

Our conversation moves back to his health concerns and he reveals to me that his doctor has also encouraged him to lose weight. Matthew tells me that he is not concerned about his diabetes risk, even though his mother had this disease. I ask him what it would mean if he were to be diagnosed with diabetes, in terms of how this might affect him on a day-to-day basis. He initially says it would be no problem, then reconsiders and says he is not actually sure. His cholesterol levels have been high, he has been told. This caused him some concern, “Ya, I had to cut back on my fats and stuff” (Matthew: T7). He takes a medication to help lower his cholesterol levels but nothing for blood pressure.

I have a sense of familiarity with this subject of schizophrenia and diabetes that tells me there is something in what Matthew is not saying. I decide to stop the tape as I feel this the conversation is going nowhere. Off tape we talk of his artwork and the benefit that this type of activity can bring a person. The tape recorder is running again and Matthew begins telling me he likes to write and draw, “I don’t do it every day, I’m sort of have, haven’t been doing it recently...’cause I sort of have some...writer’s block, but um, I may get back to doing it again.” (Matthew: T7). I am not surprised but I try not to show it. While looking at his artwork, I ask him whether or not anyone has informed

him of his risk for diabetes. Matthew responds, this time surprising me, “Ya, my doctor said that he, that I was diabetic, but he never gave me any medication and never brought it up after that” (Matthew). Matthew tells me that this was only last year. He tells me he has received no recommendations or advice, except perhaps for the weight loss. He has not been referred to the DEC, “No, not that I know of, no” (Matthew). I ask him if he would be interested in attending for the education and support to learn about diabetes and how to help manage this condition. Matthew says simply, “No”.

I offer to tell him what the DEC would offer and he replies, “If you want” (Matthew: T7). Matthew wonders how he could have diabetes since his doctor has not given him any medications for this disease. I inform him of the typical progressive nature to this condition, that things like healthy eating and active living are often where things begin, but it time medications are often required to help keep blood sugar levels as close to normal as possible. Matthew is becoming more interested in this conversation, asking, “That’s all they do sometimes?” and “So I could be diabetic?” and “they don’t do anything for it though?” and “So I may be one of those types that don’t? [need medications]” (Matthew).

Matthew changed his mind about attending the DEC and agrees to speak to his case manager later about being referred to learn more about this condition that he thought or hoped that he did not have. I know that he has followed through on making it to the DEC for several appointments, both with nurses and with dieticians for follow-up.

As I come to this place in my writing, on the conversation with the participants, I have realized, as Gadamer (1991) predicts, “the interpretive concepts are not, as such, thematic in understanding. Rather, it is their nature to disappear behind what they bring to

speech in interpretation” (p. 398). The writing on the conversations has not been organized by theme although as the conversations did take a life of their own, the discussions did tend to flow from one subject to another. The text here was not intended to be as Gadamer states, “understood as an expression of life but with respect to what it says” (p. 398), although some of it I have written in that way with the intention to highlight the subject matter on which the text speaks: “All interpretation is highlighting” (Gadamer, p. 400).

While the sense of my conversations with the participants can be realized as a unity, it is significant that the subject matter of which the text speaks is also understood. Interpretation is not the means through which understanding is achieved but contained within the process of understanding, and when concerned with understanding and interpreting verbal texts, interpretation shows what understanding always is: “assimilating what is said until it becomes one’s own” (Gadamer, 1991, p. 398). I continue, therefore, with writing from the “outside in” as I am not yet done with assimilating what has been said on this subject. Writing in this way, from the inside out and from the outside in, makes my writing more readable than if I were to attempt to write this all at once, although this would be more reflective of the process of events as they happened.

Chapter 5: The Outer Circle: Problems of the Environment

Textual Multiplicity

The conversations on living with schizophrenia and diabetes as presented here in this research speak to the complexity, ambiguity, multiplicity and the *living familiarity* of a subject that has struck me with all its impossibility. As Jardine (1998) states, although the interpretation is linked to me, it is not about me and my past experiences, “but that *of which* I have had certain experiences” (p. 44). These experiences are Joe Bell and his unwavering faith in his physicians; Al with his knowing but his inability to remember; Greg knowing but not doing; John with all the awareness but the inability to stick with it; Randy who does not know to care; Laurie and her hopelessness to lose the weight; and Matthew and his good intentions. My experiences are also the hope that things will work out for these participants, the denial that helps them get by, the support that keeps them going, and the doing of only what they are able to manage. The significance of the subject matter may not be found in the next person encountering schizophrenia and diabetes, as this would be to say that what is understandable here will also be true to others. My concern is that the words of these participants and of mine speak to what is true for us in coming to an understanding on this subject, and to a significance that is not linked to the frequency of events but to the meaning of them.

“The task of interpretation is to bring out this evocative given in all its tangled ambiguity, to follow its evocations and the entrails of sense and significance that are wound up with it” (Jardine, 1998, p. 40). In this research, if what is *significant* is able to make a claim, it is not to offer a single realization or single voice on the matter, but one to “open us up and reveal something to us about our lives together” (Jardine, p. 40), and

in this way lead to an understanding that can be used to enhance the human condition. What these participants have brought to this research is the opening up of my thinking and of my practice in the field of helping people to live with chronic conditions. It has been through what each of us has brought into the moment in conversation that provokes our former understandings and in this way disrupts our horizons to offer a new way of thinking. “Interpretive understanding opens up the possibility of seeing things differently and of orienting oneself in other ways in the world” (Geanellos, 2000, p. 114).

The participants in this study may speak to their own experiences but they speak also to the experience of *being* with schizophrenia and diabetes. The multiple experiences that emerge from the conversations represent one of the concerns of hermeneutics: “textual multiplicity: the many layers of meanings able to be construed from a text” (Geanellos, 1998, p. 154). Understanding and interpretation, the primary concerns of hermeneutics, includes not only the concern of the nature of understanding, which has been dealt with in earlier sections of my writing, but the concern of textual plurality, or how interpreters, through the influence of their preunderstandings, engage in the question and answer process to bring the text into understanding (Geanellos).

The experiences of the participants also serve as a departure into another conversation, from what the text says to what it talks about, with my understandings and preunderstandings visible “as a possibility that one brings into play and puts at risk, and that helps one truly to make one’s own what the text says” (Gadamer, 1991, p. 388). Although I proceed with the concern of whether I have ‘got this right’—the experiences of those with whom I have had conversations on this subject—whether these were paradigm cases or exemplars, I consider what Forster (in Geanellos, 2000) reminds us,

“understanding, however, seeks to go beyond what is expressed to the unexpressed” (p. 115). And while I have been concerned about the challenges of the encounter with diabetes for those living with schizophrenia, I move to the significance of what I have understood about this occurrence, revealing and putting at risk my knowing—what I think was right—to remain open to the possibility of returning to new understandings.

It is impossible for me to say when this research began. I would like to say its origins grew from when I entered the role as a clinical educator in diabetes services, bringing with me an understanding of the population living with schizophrenia and my preconceptions of the unmanageability of these two conditions but that would not establish a sufficient departure between me and my past experiences and the instance of this inquiry. This, I believe, speaks to the reliability of what the text speaks, and separating out in advance “which features of my own reading reveal nothing more than idiosyncrasies of my individual experiences and which features reveal something more” as Jardine (1998) explains, that can occur only as “I let my preunderstandings fully engage this text” (p. 44). As I acknowledge that this text is linked to me, it is about “that *of which* I have had significant experiences” (Jardine, p. 44) therefore “detached from all its contingent factors and grasped in its full ideality” (Gadamer, 1991, p. 394) that alone has validity and becomes more than unfamiliar opinion but always *possible truth* (Gadamer).

The Trappings of the Environment

A concept of the world—a linguistic constitution—is opposed to a concept of the environment, which all living beings in the world possess.

Gadamer, *Truth and Method*, (2004).

To have a world means to have an orientation toward it, and to have an orientation to the world as Gadamer (2004) clarifies means to keep oneself free from what one encounters of the world so that one can present it to oneself as it is. Freedom from the environment implies the linguistic constitution of the world: “The capacity is at once to have a world and have a language” (p. 440). To rise above the environment means “rising to the world itself, to true environment” (Gadamer, p. 442). In relating language to the world Gadamer refers to “*factualness*”, a concept for “matters of fact” that come into language as *things* that become visible, or “foregrounded”, because they behave in various ways, permitting one to recognize the independent otherness between the speaker and the thing (p. 442). The world of those living with schizophrenia who encounter diabetes contains all the multiplicity that presents in dialogue, allowing the possibilities of understanding to emerge in the true locus of hermeneutics: “this in-between” the details of the environment and our linguistic constitution of our world (Gadamer, 2004, p. 295).

The Question of Knowing

“To interpret the unexpressed within a text, the true hermeneutic endeavour requires interpretation drawing on the interpreter’s preunderstandings”

Geanellos, (2000, p. 115).

How is knowing possible? I should be asking, “How is knowing not possible?” or “Is awareness necessary in order to know?” There has been no shared agreement on the need for change in terms of the degree of risk for diabetes or its complications in the conversations with Greg, Joe, Randy, or Matthew, but that was not the point of these conversations. I do not arrive at this in conversation with Greg but that was not expected.

Agreement is expected to have happened between Greg and the diabetes team or support workers or physician or parents or whoever else told him that he needs to do things differently, so that he can surpass that ten more years, but it is clear that it has not: “I get Creamsicles or ice cream, frozen foods. I can deal with most [foods]” (Greg: Transcript 3). The process of reaching a common agreement does not easily occur between people who are unable to engage in conversation with each other, yet I have viewed awareness as the opening to *knowing*, thinking that this would solve the problems of living at unnecessary risk for health complications due to their *lifestyle*. If there are barriers to the dialogue process, then there is a barrier to coming to an agreement. What then do we rely on for achieving this goal? When our usual methods are inadequate? Do I know if Greg has a limited capacity for knowing how at risk he is for blindness, kidney failure, or for amputation? Do I know that clarifying his risk for diabetes-related complications would result in distress that would result in possible relapse of his psychotic symptoms? Can I affect his lack of knowing, and even if I do, what then?

The conversations with the participants show that even *with* knowing, action or following through on an idea or plan is often not possible, as in John’s responses:

I still struggle with my routine things because um like trying to maintain a regular ah exercise routine is um somewhat challenging. Um, I suspect it has something to do with...um this sort of cycling of ups and downs...

...When I’m in the bottom end of my, um, emotions, when I’m sort of feeling like I want to give up or give in, then that’s when those, those things start to, um, I start to lose perspective...

...Um I, I think what I need to do is find something that um that’s not, not a chore to do you know, that’s, that’s a very key point, I think, is, is, is having something that has meaning to me, or to anybody, um to, to, to find that interest in the, in the activity that you need to do to keep well is important, right? ...

...I think like there's, there's certain limitations to what you can and can't do in terms of exercise because there are only so many classes and so many um, um, organizations or groups that people are putting on....

...I just, you know there is something that has to happen to give you that, to give me my motivation to...stick with it...

...my thoughts that are trapping me in that apartment, keeping me, um, ah, undercover and keeping me away from going out in the community and being involved in things...

...when I'm not doing those sorts of things, I become ah, you might say, socially embarrassed...

...Those barriers are, are inside of me, they're, they're in my mind, that I don't want, um, to share... (John: Transcript 4).

And as with Laurie:

No, I've been concerned about my health since I started getting sick, you know, at that point...

...It was a concern but I seemed really helpless to do anything about it...

...It's always fighting that, the desire to want to eat...

...I was so depressed; I wanted to do any more sleeping and eating, you know, because work was no longer part of my life...

...Um, the better days are that I have something to do, you know, to get up and get going for, but still it's like I've slept till 11:00, right? Even though I had my alarm on for earlier, I just kept hitting the snooze and, you know, I'm just so tired and I don't wake up when I should be waking up. The medication and stuff (Laurie: Transcript 6).

Al is aware too that in the event he does develop diabetes, he would likely not do the things that he knows he should: "It probably would because I'm, I'm one to forget.

That's why, that's why I'm scared just sort of remembering to take ah the medication"

(Al: Transcript 2).

An assumption of all major therapies, including the trans-theoretical approach to the process of change from Prochaska and Diclemente (Prochaska, Norcross & Diclemente, 1994) “begin by trying to raise your level of awareness, increasing the amount of information available to you, and thus likelihood of your making intelligent decisions concerning your problem” (p. 27). Prochaska’s change theory is central to approaches used in patient counselling among diabetes educators, however the assumption is that patients *can* change, and that people should, however, as seen with Laurie and her relentless struggle with depression and interest only in sleeping and eating, not wanting to risk another medication change for fear of another psychotic episode, or John and his residual symptoms that keep him keenly aware of the barriers within his own mind, I am left feeling ill-equipped to make a difference. I have no answers to what I now realize have been problems and not really questions, but I further my understanding of the possibilities, through the hermeneutical spiral, as it were, to arrive at what is at stake with the encounter of these two chronic conditions.

Schizophrenia-ism: Prejudice is Preunderstanding

Do we take the misunderstandings of the concepts of health and illness or the healthcare practices that do or do not exist for people with schizophrenia for granted? Do we take at face value what the other says to us in the dialogue about their health? The essence of the question leads us to the opening up of possibilities for understanding (Gadamer, 1990) but as Gadamer also informs, in order to make a judgement we, of necessity, have to have a yardstick or a *tradition* within which we always find ourselves. While these questions represent a *tradition* of what is at play in this subject, it is not to say that the tradition is in stasis. “We humans have created tradition and can—and do—

change it on a regular basis” (Debessay, Nåden & Slettebø, 2008). There is little doubt in the world of diabetes self-management that education, awareness, resources, and support, are essential factors for attending to the demands of this progressive condition as the so called ‘pillars of management’—diet, exercise, and medications—become aligned to meet the patient’s presentation . There is little doubt too on the risks of poor management and the benefits of good control, from the multi-site clinical research trials that have been covered earlier in this writing. But what is happening within a population that presents differently to the majority? What is happening in the patients’ responses and in ours as we meet in the encounter of schizophrenia and diabetes?

I speak to a dietitian, Laura, on the 27th of April, who has worked directly in mental health services providing dietary support in a tertiary care facility, about my preunderstanding—about this notion of neglect that I believe is occurring during people like Greg’s and other patients who visit the DEC who have serious mental health challenges. Laura recognizes this perception and suggests that it is more of a system’s problem than one of care giver neglect. We talk about the issue of resources, that it is the limited resources—mostly that the amount of time available for each client is limited—that prevents us from providing the adequate support or resources to help those like Greg in ways that would be required. His support worker should be present at appointments, we agree, so that what we recommend could be reinforced through repetition by his support worker as this is what people with serious mental illness require if they are going to be successful with lifestyle changes. Laura describes the problem she has encountered with patients’ support workers with regard to their role in providing life skills around the subject of nutrition. In Laura’s attempts to provide education for the care giver, she has

realized that the psychiatric rehabilitation workers (PRW's) appear to be motivated to provide shopping and cooking support in ways that reflect their own nutritional habits or meet their own needs rather than the nutritional needs of the patients. By this she explains that food becomes a reward—a treat—that makes the environment and the patient-PSW relationship more pleasant. Laura's attempts at implementing healthier choices are met with resistance at the caregiver level, which serves to preserve a tradition that has developed within the tertiary care setting.

We move on to discuss the barriers to learning that include our inability to know—or the patients' inability to express—if what we provide in the way of information is understood. We remind ourselves that, it is the message received and not the message given that is important (Vallis, 2004). My colleague also acknowledges her own need to feel rewarded from doing her job well. From knowing that she made a difference. And with certain clients, the very old, the unmotivated, or the severely mentally ill, it is more difficult to do the job well and feel rewarded because it is harder to make a difference.

Another discussion takes place with Patty, a dietician who is another colleague. Patty tells me of her experience with working with a young woman in her 20's with schizophrenia and diabetes. This young patient, like Laurie, had gained an enormous amount of weight after starting on psychotropic medications. Patty tells me that it took her an entire year of repeated appointments to get this patient to stop drinking iced tea: "The penny dropped when my patient realized that she had no more vaginal infections with better blood sugar levels" (personal communication, June 1, 2007). Patty summarizes her concerns: "It's hard to know if you are connecting with the patient and

we need it's not personal—that they're not disinterested—and we need to see these vulnerable people more often than the resources allow”.

The following week I meet with Susan, another dietician, this time one who works in the in-patient setting of the psychiatric hospital. Susan and I discuss the concern about the unavailability of nutrition support for the psychiatric patients who are in hospital and starting on the medications and the other encounters with their disease that puts them at risk for weight gain and diabetes. Susan tells me that as she only has a three day per week position, her time is monopolized by the patient population with eating disorders such as anorexia and bulimia. Susan claims that she has been directed to focus on the population with eating disorders as her involvement is known to reduce the length-of-stay in hospital.

I reflect back on Greg's appointments to the DEC and the problems regarding the quality of care: there is no consistency in the team members who see Greg; he will see one of three dieticians and one of three nurses; and there is no plan or identified goal on his out-patient chart. I try to recall the last time I or anyone reviewed what the targets of blood glucose should be—not as Greg says, “Between 10 and 15” (Greg: Transcript 3), where he feels best—or described what a balanced meal actually looks like, or provided sample menu plans that would be as affordable but more nutritious than what Greg is eating or why any of this is important. He has not been brought back to see a dietician or nurse for an individual appointment, rather he returns every 6 weeks or so to sit with his case worker, the endocrinologist, and the nurse and dietician, with the discussion focused on encouraging Greg to be more consistent in taking his insulin or monitoring his blood glucose levels. Sometimes his insulin doses are adjusted, but he always runs in the 10%

A1c level (normal is 4.5-6%). We recognize the possibility that we have given up on the more detailed aspects of his diabetes management, mainly focusing on the emergent issues, such as the past hospitalization for hyperglycemia that occurred because Greg missed too many insulin injections. The focus, we agree, is on the acute care incidents rather than on preventative aspects of Greg's care and I question whether this unintended neglect occurs with the population with schizophrenia in general.

I return to conversations with two other colleagues, Bonny, an in-patient diabetes nurse educator and Janine, a clinical dietician, to discuss this notion of neglect, and again my first attempt to convey my assumption is met by efforts of rationalization for the apparent lack of appropriate care. It's a time limitation issue: Greg has been helped by the frequent visits to the clinic. He has come a long way I realize. All that is true and I reflect on the progress this individual has made however slow it has been. He is taking his own insulin on a more consistent basis. He is able to regain the weight that he loses when hyperglycemic for weeks or months at a time. His leg ulcer is healed. He does like to come to the clinic, and in our conversation he does acknowledge what he believes we have done, even if this was not what we intended:

I like it when they care and when love is there but when it's not, when you're dealing with stressed-out people like that, it, it makes it all much harder. But they're loving and caring, they help you, they hold your hand, they pick you up off your feet, and stuff like that...(Greg: Transcript 3).

But Greg is doing so much more poorly than he should be. I ask my colleagues, Janine and Bonny, whether they think people with serious mental illness receive a different standard of care than others who are not living with schizophrenia because *they* do not ask the same of us. Are the messages that we give to clients like Greg possibly of lower quality? I suggest that what we offer is less, that people like Greg often do not

receive the review independent from the endocrinologist-driven appointment that others would have been offered if they presented with the equal level of misunderstanding, or if they requested it. My colleagues pause, and then agree. “You’re right. It’s like racism, or ageism” Bonny tells me. “You aren’t really aware of it but you catch yourself oversimplifying the educational content and you probably don’t need to. Or you need to find ways to help the person understand, but because it is a different way of interacting than we are used to, effective education does not happen or it happens poorly” (personal communication, May 5, 2008). We discuss the parallels between these other “isms” and reach agreement that there is more that we could do for individuals like Greg: Bring him in to inquire what he knows about his diabetes. Review healthy eating. Offer support for a meal plan and shopping list. Invite his case worker to his individual appointment.

Next day, another in-patient diabetes nurse educator, enters the discussion. The same initial reaction occurs: “It’s hard to make a difference with some clients. You don’t know what they understand after you have seen them and I think you can only do so much” (Jane, personal communication May 6, 2008). I tell her that learning new skills for people with psychotic disorders requires repeated practice with a new task, such as with the preparation of a meal, and they do very well with the proper supports. I also speculate that the difficulty with imparting understanding might lie in our own limitations and not only with the client who is living with a severe mental illness, that we might provide less of the didactic content than we would if the client was more able to express appreciation or understanding. We discuss the assumption I bring to this subject regarding the care outcomes for people with diabetes and schizophrenia. I have approached this project with the expectation that outcomes between people with or

without schizophrenia should be equal, and now I am wondering if this is realistic. But how many years of reduced life expectancy or years without co-morbidity are acceptable for people with schizophrenia? Why is this acceptable that people's quality of life is reduced because health care providers are not able to arrive at an appropriate solution? Is there a solution possible? These questions form like doubts in my mind, that perhaps the taken-for-granted disparity of care outcomes for the population with schizophrenia is simply a reflection of the complexity, ambiguity, tragedy, and the possibility and impossibility of the co-occurrence of schizophrenia and diabetes.

In looking to the literature on studies that have examined the possibility that people with schizophrenia may experience a poorer quality of care, I am left questioning. Goldberg, Kreyenbuhl, Medoff et al. (2007) report evidence of lower quality of diabetes care for persons with serious mental illness as reflected by their receipt of fewer recommended services and less education about diabetes, compared with those without serious mental illness. Although participants with serious mental illness received some services that are indicated in quality of care standards for diabetes, they were less likely to receive the full complement of recommended services and support, suggesting that more effort may be required to provide optimal diabetes care to these vulnerable patients. These authors looked at the quality of diabetes care provided to persons with serious mental illness from four studies in all, three of which were conducted in the Department of Veterans Affairs (VA) or drew from the VA population, and one retrospective study which included a group of privately insured people with and without mental disorders.

Authors Whyte, Penny, Phelan, Hippisley-Cox, and Majeed (2007) also looked at whether patients with schizophrenia receive poorer quality of diabetes care compared to

patients without mental illness. These authors examined the records of over 11,000 patients with diabetes from 481 UK general practices and were unable to prove their hypothesis. Rather, they found surprisingly that the number of patients achieving an A1c of less than 7% were higher in those schizophrenia than without.

Studies reporting the association between metabolic abnormalities including weight gain for patients with schizophrenia taking typical versus atypical antipsychotic medications are equally unclear. Holt, Peveler and Byrne (2004) searched the literature from PubMed and MEDLINE on schizophrenia, the metabolic syndrome and diabetes, and drawing on 289 abstracts with the relevant papers obtained, provide a good summary on the relationships between schizophrenia and the metabolic concerns. In general, diabetes risk among people with schizophrenia is reported to range between two to four times that of the population without severe mental illness. There is considerable debate, however, on the relative risk for developing weight gain or diabetes with the various atypical antipsychotic medications, mainly due to the difficulty in interpreting these studies (Holt, Peveler & Byrne). The ambiguity of the literature on things such as quality of diabetes care for people with schizophrenia or the relationship between medications and metabolic abnormalities only serves to reinforce my understandings and misunderstandings on the details of the environment, of this world and of a tradition that remains a basis for this hermeneutic endeavour.

Challenging the Inseparability and Impossibility

In Gadamer's (2004) discussion on language as experience of the world, he refers to Wilhelm von Humboldt to explain that interest in individuality is not a turning away from the universality of the concept. Rather there exists an "indissoluble connection

between individuality and universal nature” (Gadamer, p. 437). The individuality of each participant in this study informs the universal nature of the encounter between the particular chronic conditions of schizophrenia and diabetes, through what has become visible to me as concepts of awareness, knowing, insight, and the ability or inability to initiate and maintain what we believe to be are *lifestyle choices*. As I listen to the texts and become involved in what is understood, a realization emerges that lifestyle choices are often not really choices at all but details of the complex world of those living with schizophrenia concerned of the risks of diabetes. There are other details too, that speak to and challenge that of which I have already understood: the impossibility and hopelessness of two chronic conditions that seem *inseparable and unmanageable* all at once. There is the individuality of the capacity to *overcome the barriers*:

...there’s usually a point where it’s just too much, where I just can’t bear it anymore and I have to do something about it....I have to organize my apartment, clean my apartment....I just have to get outside and I have to go to the store to do something, to get out and, and remind myself that I’m a part of this community and that I need to, I need to get out and be a, do that, and be a part of the community...It was just too—it was very, very intense and, um, so I knew, I knew from there it was almost, it was almost an instinct, that I needed to do something about it. I didn’t really need anybody to tell me that I needed to do anything, I knew it because it was so...(John: Transcript 4).

There is also the individuality that informs the concept of *hope*. Even Laurie, who has so little hope, is able to express a tangible amount: “Um, I’m struggling with depression a little bit. Not as bad as it was in the winter. I can see an improvement” (Laurie:

Transcript 6). And there is hope for Randy that is discernable in what he is able to share:

I’d try to get food whenever I can, just to, just stock up which is, I wanted to get fat when I was living on my own just because then I wouldn’t have to worry about getting too skinny, right?...Slowly, slowly but surely, I just kind of, after a few months of that, not eating right, you start to feel totally drained, you know? (Randy: Transcript 5).

There is a perspective, which is understandable perhaps only to the individual but which speaks to a different type of manageability of life with schizophrenia, and that is one of *acceptance*: “Very lucky. There’s always food in the fridge...Clothing allowance...and food...and shelter and...very lucky to be here” (Al: Transcript 2). Joe speaks to his acceptance of the twice daily blood glucose testing and insulin injections, “Yeah, it’s part of my life, this is part of my life” (Transcript 1), and his ability to carry on, “Yeah, mistakes are the past. I remember. And I don’t do ‘em anymore”. John finds what has helped him accept his circumstance and how he knows he will survive:

But the most important thing about what’s helped me the most is that I’ve found in, in myself some, some, somewhere that there was um I, I found reasons for my, the way, the way, how my downfall happened. I found avenues to express myself so that people around me had a better idea of what was going on and professionals that I needed to express to them, what was going on—not only just basic symptoms but, you know, kind of in a story, like, say, setting, just to, so that they had a picture of what was going on...(John: Transcript 4).

Perhaps what helps each individual in overcoming the inseparability and impossibility of these conditions is the capacity of others to *care*:

And, ah, again, I thank God for Dr. Ford. He’s helped me a lot. He’s done a lot for me... He, he even just meets sometimes when he doesn’t even have to. He’s coming on Wednesday again. He comes, sometimes he comes every 2 weeks, and then if I’ve been doing o.k. for the month, then it’s once a month. He comes and sees me here....Yeah, if she wouldn’t have been there, maybe somebody else would, would have been some other woman, ‘Ah just a drunk’, you know, and it makes you look a drunk you’re your legs and arms aren’t working (Joe: Transcript 1).

He’s [the endocrinologist] helping save my life, right? I want to live for at least another 10 years....If they weren’t there, I don’t think I’d be living right now. You know, I’d be like way in whatever you call it, debt, like, really far fucking gone from reality... (Greg: Transcript 3).

The Complete Circle

To make a good metaphor is to recognize a good comparison.

Aristotle, *Poetics*

The understanding—the ethics of health care delivery, the value of knowing, the revealing of our biases, the inseparability and impossibility—that has emerged between the horizons of the researcher and participant in this study represent some of the truths that exist in the world and that are shared by those who encounter the subject of schizophrenia and diabetes. The concern of coming to an understanding for anyone sharing in this subject lies in the ability to hold at a distance the subject from its individual parts. In this way, Gadamer’s philosophical description of how we understand—the circular process in which we move from a whole to the individual parts—depends on this conceptual ability of creating this distance. To see what is hidden, we need to separate it from its background, in this way separating our concept of the world from our environment.

Perhaps we are all doing the best we can. Perhaps the diabetes care that patients with schizophrenia receive, good or bad, intended or unintended, is what Gadamer (2004) refers to as the concept of *tradition*: the “world of shared history, language and culture which prefigures understanding” (Geanellos, 2000). But in sorting out the traditional text, or “how to distinguish the true prejudices, by which we *understand*, from the false ones, by which we *misunderstand*” (Gadamer, 2004, P. 298), a certain distance or foregrounding is required between our prejudices so that the “text, as another’s meaning, can be isolated and valued on its own” (Gadamer, p. 298). Gadamer explains that the way of making our prejudices known occurs through provoking our prejudices through the encounter with the text. Understanding begins when something addresses us, as it asserts itself on its own validity “between the traditional text’s strangeness and familiarity to

us, between being a historically intended, distanced object and belonging to a tradition.

The true hermeneutics is this in between" (Gadamer, p. 295).

To bring together the parts of a subject into one whole is a criterion that Gadamer (2004) refers to as proper understanding, and understanding may only be possible through dialogue (Gadamer, 1993). This philosophy of how we understand applies not only to researchers and participants but to any two individuals, including health care professionals and clients. Nurses are uniquely positioned to respond to the encounter of schizophrenia and diabetes and through engaging in dialogue with others, questioning assumptions and challenging their pre-understandings, they may provoke ethical action to open possibilities to reduce the burden of this encounter and prevent the catastrophic consequences experienced by those living with these two chronic conditions.

We need to be able to continue in dialogue—in conversation—with one another to keep ourselves free of the trappings of our environment—to be able to maintain an orientation to our world and all things it contains—and in this way continue with the generative nature of understanding through our conversations on the subject of encountering diabetes for people living with schizophrenia. So it can be just as John struggles to articulate, a coming to an understanding through the dialogue with one another:

My, my vision right now of what I need to do? Going to, you know, we talked a little bit about diabetes, is that my vision now of what I need to do to prevent me from, from an illness like that is, is much more clear, I have a direction, I have, um I have a better sense of like, going back to what you were saying, control of myself, control of my thoughts and, and allowing me to do the things that I want to do to keep myself from getting diabetes....I think there is a, a link between the two illnesses, I believe that we are, um, as a schizophrenic who takes a certain amount of medication, I think that we're sort of, we are at risk, more at risk, of getting diabetes so I want to change some of my, you know, like little bits, little bit at a time, you know, just sort of add this, try this, see if that, you know, if

that's, and you know, and have some dialogue with, with support people but like, you know, you just, just...(John: Transcript 4).

...Continue on, “to make what has been said of the experience, in the past readable again by reopening it to new, generative instances (Jardine, 1998, p. 41). Interpretation is always application (Gadamer, 2004).

The Ongoing Journey

It is a central principle in hermeneutic philosophy that understanding is approximate and incomplete and that interpretive diversity, arising from differences in interpreter pre-understandings and the questioning of the text from particular perspectives, is both part of the uncertainty and strength of interpretive research (Geanellos, 1998). The question I have asked myself throughout this journey is will any of this make a difference? Has this research project enabled me or anyone else to understand the encounter of schizophrenia and diabetes that is experienced by the population living with these chronic conditions? The question of how we understand anything at all is central to hermeneutic inquiry and the way to reveal a phenomenon under investigation is “to engage with the text [or in conversation with another] within the hermeneutic circle by addressing pre-understandings, reflecting on their origins, adequacy and legitimacy, and considering their influence on the research/er” (Geanellos, 1998, p. 161). The intent of this project was also to open this subject to questioning—or to what is questionable—and to offer possibilities for understanding about this seemingly impossible and often tragic event that exists between these two chronic health challenges. The encounter of diabetes for people living with schizophrenia is an event that in some ways is not different than the challenges experienced by any of us who struggle with

adapting to the demands and expectations that accompany the diagnosis of a chronic condition, yet there is an experience that is unique in this encounter and one that needs to be explored further in research to continue the deepening of our understanding of this concern.

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Appendix A

UNIVERSITY OF VICTORIA/ VANCOUVER
ISLAND HEALTH AUTHORITY (VIHA)
OFFICE OF THE VICE-PRESIDENT, RESEARCH
HUMAN RESEARCH ETHICS COMMITTEE

Participant Consent Form

Research Project:

Understanding the Encounter of Diabetes for People Living with Schizophrenia

Principal investigator: James Morrell, Graduate Student, University of Victoria
Supervisor: Dr. Carol McDonald, Assistant Professor, University of Victoria

The purpose of this consent form is to provide you with information about the nature of this research and what your participation will involve. Please take time to read this carefully, and feel free to ask if you wish to know more regarding this study.

You are being invited to participate in a study entitled “Understanding the Encounter of Diabetes for People Living with Schizophrenia” that is being conducted by the researcher, James Morrell. James is a Graduate Student in the School of Nursing at the University of Victoria and you may contact him if you have further questions at: 370-8111 local 2219

As a Graduate student, James is required to conduct research as part of the requirements for a degree in the Master’s program, *Advanced Nursing Practice in Leadership*. This research is being conducted under the supervision of Carol McDonald. You may contact her by telephone in Victoria at: 472-5280

If you have any questions regarding research participants’ rights, you may contact Dr. Peter Kirk, Regional Director of Research and academic Development, Vancouver Island Health Authority (VIHA) at (250) 370- 8620.

Funding:

This research is not being funded by any external funding agency. Any change in this regard will require the future consent of all study participants should funding come available.

Purpose of Study:

The purpose of this research project is to increase the understanding on the subject of living with diabetes (or with the risk of diabetes) for people who are already living with schizophrenia.

Research of this type is important because:

There is limited research on the experiences of people who live with both schizophrenia and diabetes. As a diabetes educator, and a nurse who has worked in mental health, I believe that people living with these two conditions have a unique set of challenges, and therefore require special consideration. Health care providers need to understand what these challenges are to better inform changes to existing health care practices for improved quality of life for people living with diabetes and schizophrenia.

You are being asked to participate in this study because:

You meet the inclusion criteria for the study, which includes awareness of your diagnosis of schizophrenia and diabetes (or if you are concerned about your risk for diabetes), being over the age of 19 years, and having expressed interest in the subject of living with these two conditions.

What is involved:

If you participate in this study, the researcher will ask you to talk about your own experiences of living with schizophrenia and diabetes. **Other things you should know before you agree to participate include:**

1. The conversation with the researcher will take about 1 hour.
2. The conversation will be tape recorded and converted to written text.
3. The conversation will take place in a private location that you choose: in your own residence, or in an office, either at the Diabetes Education Centre, or the Victoria Mental Health Centre, located at the Jubilee Hospital.
4. Your identity will remain private: Your name will not appear on any file or text, but to ensure confidentiality, you will be asked to provide an alternate name that will be used for all record-keeping of the conversation. Some of what you will talk about will be shared with the research supervisor and the two members of the research committee, although your personal identity will not be shared with anyone involved in the research.
5. There is no identified risk for participating in this study. However, you may find that you feel emotional or uncomfortable with what comes up during the conversation. You have the right to stop the conversation at any time and to withdraw from the study. The researcher will offer to assist you with connecting to your case manager or your identified support person if you think this would be helpful.
6. There is no financial compensation available for your participation in this study – participation is purely voluntary.
7. *Potential benefits* for your participation in this research includes contributing to our understanding of living with schizophrenia and diabetes. The potential for increasing understanding on this subject may also be useful for others who read the research findings, particularly those involved in delivering health care.

Withdrawal from Study at a later date:

Your participation in this research must be voluntary. Even if you have decided to participate, you may decline to answer any question during the interview or you may withdraw from the study at any time without negative consequence. If you do withdraw from the study, your data will be either used in the analysis or be destroyed, depending on what you prefer. You have a right to withdraw your consent from the study and have your information removed and destroyed up until the point when your information has already been analyzed. After this time, the researcher reserves the right to retain the data for completion and publication of this research.

Dual Role of Researcher:

The researcher, who works also as a diabetes nurse educator at the Diabetes Education Centre, located at the Royal Jubilee Hospital in Victoria, may already have a professional relationship to you. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken: Health Care professionals who are not involved in this study will make initial contact (this may include displaying recruitment posters in a residential care or mental health facility) to inform and obtain permission from participants to be contacted by the researcher. You will also be offered to be seen by an alternate diabetes educator if you prefer.

Protecting your anonymity:

Your identity will be protected throughout this project and in all papers and presentations regarding this study. Participants' real names will not be used and any personal identifying characteristics (of yourself or others) will be removed (or altered) from all materials related to this project. Participants' identifying characteristics will be limited to age, ethnicity, gender, diagnosis, and geographic and service region only (Vancouver Island and the Diabetes Centre at the Vancouver Island Health Authority).

Protecting Confidentiality:

All data and personal information that exists in the form of taped and transcribed conversations, researcher notes, and/or computer file formats will be securely stored in a locked file cabinet or pass-word protected computer file, accessible only by the researcher. Transcription of the recordings will be done in a private and professional setting by one of the secretaries from the University of Victoria's Nursing department. Names, phone numbers, and addresses of participants will not occur directly on data files, rather identification numbers will be used and cross-referenced to a separate format to be only used by the researcher to clarify any part of the conversation. Access to all information will be limited to the researcher who will also ensure confidentiality of participants at all times, including when discussing data with the research committee. Limits on anonymity and confidentiality may occur from the small number of participants in a setting such that you could be identified (depending on location of interview).

Sharing of results:

The communication of results upon completion of this study is an important part of the research process. The potential for improving health care practices, guiding further research, and shaping policy decisions which translates to an improved quality of life for all people living with diabetes depends on the findings from this study to be made accessible to others. It is anticipated that the results of this study will be shared with others in the following ways: directly to participants, through the thesis report, presentations to health care professionals and educators, and through published articles.

In addition to being able to contact the researcher and the supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President Research at (250) 472-4545 or ovprhe@uvic.ca.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

<i>Name of Participant</i>	<i>Participant's Signature</i>	<i>Date</i>
<i>Name of Researcher</i>	<i>Researcher's Signature</i>	<i>Date</i>
<i>Witness</i>	<i>Witness' Signature</i>	<i>Date</i>

A copy of this consent form will be left with you, and a copy will be kept by the researcher.