Changing the Conversation: a Critical Ethnography of Diabetes Care in People with Mental Illnesses

by

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Abstract

Chronic illnesses pose a large public health threat. Diabetes mellitus type II accounts for about 90% of cases, is largely considered preventable by health providers, but continues to be among one of the most debilitating chronic conditions in Canada, and around the world. The co-occurrence of severe mental illnesses and diabetes is well documented, with diabetes being two to three times more prevalent among individuals with severe mental illnesses, compared to the general population. In clinical practices, diabetes management for people with mental illnesses and diabetes continues to operate on the premise of chronic disease model with an understanding of diabetes as a physiological and behavioral deficiency. Therefore, clinical and policy efforts are directed toward the enhancement of patient self-management techniques through patient compliance with pharmaceutical and lifestyle behavior recommendations. Self-management continues to be an important mandate in clinical practice and public health policies, where its biomedical understanding continues to prevail. Nonetheless, relatively little attention has been given to the exploration of how well the biomedical model aligns with
people’s everyday experiences. This project explored everyday experiences of diabetes self-management and biomedical compliance among those diagnosed with severe mental illnesses through the lens of critical ethnography. This work demonstrated discordance between biomedical perspectives on diabetes management and the lived experiences of those with mental illness. I identified an alternative conceptualization of diabetes management that moved beyond idealized concepts of self-care in order to introduce the social realities of people with severe mental illnesses as they attempt to enact and negotiate around medical directives. This new understanding encourages a shift towards broader social and contextual understandings of the lived realities of individuals with severe mental illness, and their resourcefulness, competence, persistence, and capabilities. Attention to how social context informs patients’ realities may assist in the development of new context-sensitive and patient-oriented grounds for public health strategies and clinical practices associated with diabetes care, and challenge traditional understandings of compliance and noncompliance with diabetic self-management.
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# Table of Contents

Abstract......................................................................................................................................................... ii

Acknowledgments ........................................................................................................................................ iv

Table of Contents........................................................................................................................................ vi

Chapter 1: Introduction................................................................................................................................. 1

Overview...................................................................................................................................................... 1

Relevance and Scope .................................................................................................................................. 1

Purpose ....................................................................................................................................................... 1

Positioning: Diabetes as a Medical Problem ............................................................................................... 3

Rationale ..................................................................................................................................................... 4

Study Objectives ....................................................................................................................................... 5

Thesis Organization ................................................................................................................................. 6

Thesis Terminology .................................................................................................................................... 8

My Standpoint ........................................................................................................................................... 1

Chapter 2: Meet Brian ................................................................................................................................. 4

Introduction............................................................................................................................................... 4

Locating Brian .......................................................................................................................................... 4

One Day from Brian’s Life ....................................................................................................................... 6

Summary.................................................................................................................................................... 9
Chapter 3: Literature Review

Introduction
Search Strategy
Conceptual Appraisal
Epidemiological Literature on Diabetes Management
Causation Literature on Diabetes in the Presence of Severe Mental Illnesses
  *Diabetes as Inherited*
  *Diabetes as Acquired*
Intervention Literature on Diabetes
  *The Concept of Self-Management*
  *The Concept of Compliance*
Summary
Social Science Literature on Diabetes Management
Introduction
The Social Construction of Illness Experience
  *Illness Experience through the Lens of Critical Perspective*
  *Structural Processes as Revealed through Individual Practices*
Diabetes Management Experience through the Critical Perspective
  *Ethnographic Accounts*
Chapter Summary
Chapter 4: Research Design
Theoretical Framework
Critical Ethnography as a Research Inquiry
The Conversational Map: an Instrument and a Discourse ........................................... 45

Ethics .......................................................................................................................... 46

Ethical Guidelines ....................................................................................................... 47

Ethical Principles .......................................................................................................... 48

The Research Site: Family Health Team (FHT) ............................................................ 50

   *Negotiating Access* ............................................................................................... 51

   *Setting Description* .............................................................................................. 52

Research Participants .................................................................................................. 54

Recruitment .................................................................................................................. 54

Inclusion and Exclusion Criteria .................................................................................. 55

Participants ................................................................................................................... 56

Data Sources ............................................................................................................... 59

Participant Observations ............................................................................................. 59

   *Practice of Observation* ....................................................................................... 60

   *Field Notes* ........................................................................................................... 61

Participant Interviews .................................................................................................. 62

   *Patients with Severe Mental Illnesses and Diabetes* ............................................... 62

   *Health Professional and Administrator Interviews* ............................................... 65

Documentation ............................................................................................................ 65

Data Analysis Procedure ............................................................................................. 67

Quality and Rigor .......................................................................................................... 71

Conceptual Applicability .............................................................................................. 72

Verification of Knowledge Claims: Internal Coherence ............................................... 73
Critical Subjectivity ........................................................................................................ 73

Summary .......................................................................................................................... 74

Chapter 5: Findings. A Roadmap of Diabetes Management ........................................... 75

Introduction ....................................................................................................................... 75

Part One: An Entry Point ................................................................................................. 76

Mapped Realities .............................................................................................................. 76

Participants’ Experiences ................................................................................................. 77

Diagnosis Stage: A Random Discovery .......................................................................... 78

Service Provision Stage .................................................................................................... 80

Part Two: Diabetes Road Map .......................................................................................... 81

STOP ONE: Experiencing Diabetes ................................................................................ 82

Mapped Realities .............................................................................................................. 82

Participants’ Experiences ................................................................................................. 82

STOP TWO: Feelings and Emotions ............................................................................... 90

Mapped Realities .............................................................................................................. 90

Participants’ Experiences ................................................................................................. 91

Living Realities .................................................................................................................. 91

Previous Experiences with Mental Health System ...................................................... 96

STOP THREE: Complications of Diabetes .................................................................... 99

Mapped Realities .............................................................................................................. 100

Participants’ Experiences ................................................................................................. 104

STOP FOUR: Recognizing and Managing Symptoms .................................................. 105

Mapped Realities .............................................................................................................. 105

Participants’ Experiences ................................................................................................. 107
Blood Glucose Monitoring through A1C: Mandated Attendance ........................................ 112

STOP FIVE: Medications & Lifestyle Behaviors .................................................................. 114

Taking Medications ........................................................................................................ 118

Dietary Choices: The Concept of Healthy Eating ................................................................. 125

The Concept of Keeping Active .......................................................................................... 136

STOP SIX: Finish Line: Achieving Your Goals ................................................................. 140

Mapped Realities ............................................................................................................... 140

Participants’ Experiences ................................................................................................... 141

Chapter Summary .............................................................................................................. 142

Chapter 6: Changing the Conversation .............................................................................. 144

A Summary of Chapters ...................................................................................................... 144

Findings ............................................................................................................................... 145

Mapping Relationships to Previous Research ..................................................................... 148

Re-Drawing Diabetes Management Road Map ..................................................................... 152

The Treatment Landscape of Diabetes Self-Management ...................................................... 153

Practices of Navigation: Diabetes Management Detours ....................................................... 155

Strengths and Limitations ................................................................................................. 160

Study Implications for Clinical Practices and Public Health Policies ................................. 161

Research Directions ......................................................................................................... 162

Clinical Practice Directions ............................................................................................... 163

Policy Directions ............................................................................................................... 163

Conclusion .......................................................................................................................... 164

References ........................................................................................................................... 167
Appendices ........................................................................................................................................ 191

Appendix I: Conversational Map.................................................................................................. 191

Appendix II: Interview Guide I Entry-Level Informants .............................................................. 192

Appendix III: Interview Guide II Health Professionals and Administrators ............................... 193

Appendix IV: Recruitment Flyer: People Diagnosed with Severe Mental Illnesses and Diabetes .................................................................................................................................................. 194

Appendix V: Recruitment Flyer: Health Professionals and Administrators .............................. 195

Appendix VI: Informational Sheet ................................................................................................ 197

Appendix VII: Screen Sheet ........................................................................................................ 198

Appendix VIII: Observation Guide: Field Work ......................................................................... 199

Appendix IX: Informed Consent Form for People Diagnosed with Severe Mental Illnesses and Diabetes ........................................................................................................................................... 200

Appendix X: Informed Consent Form Health Professionals .......................................................... 203

Appendix XI: Global Assessment of Functioning (GAF) Scale (DSM - IV Axis V) ..................... 206

Appendix XII: Field Note Example ............................................................................................... 207

Appendix XIII: Reflective Note Example ..................................................................................... 215

Appendix XIV: Diabetes Flow Chart ............................................................................................. 216

Appendix XV: Referral Form .......................................................................................................... 217

Appendix XVI: My Goals Card ...................................................................................................... 218

Appendix XVII: Program and Services Details .......................................................................... 219

Appendix XVIII: Conversational Map Mapped Coding ............................................................... 222
Chapter 1: Introduction

Overview

This chapter introduces the study and organization of this thesis. I first describe the relevance and scope of this work. Second, I provide the rationale for the focus of this study on diabetes management by people with severe mental illnesses. Next, I present the study objectives, followed by an overview of the organization of the thesis chapters. I then clarify several terms used in this thesis. Finally, I conclude with a reflexive account of my social location, and the ways in which it influenced my doctoral project.

Relevance and Scope

Purpose

The purpose of this doctoral project was to understand the process of diabetes management, which is understood as a diverse set of daily health practices that are medically prescribed in relation to diabetic care, from the experiences of patients diagnosed with severe mental illnesses. This diverse set of daily health practices is developed out of recommendations detailed in the Canadian Diabetes Association (hereafter CDA) Clinical Practice Guidelines (Harper et al., 2013). The CDA guidelines developed as a result of collaborative work of a large number of medical professionals and are viewed in health practices as representing the best and most current evidence-based clinical practice data for healthcare professionals in relation to diabetic care (CDA, 2013). Guidelines are updated every five years and include a set of tools and articles dedicated to main aspects and clinical practices for diabetes management in different
populations (Harper et al., 2013). In this work, I was seeking to explore these diabetes care experiences in relation to what patients do and how they do it, when faced with diabetes. This included collecting experiences from patients’ perspectives through ethnographic methods, such as clinic observations, formal and informal semi-structured interviews with patients and medical providers, and analyzing these experiences using a critical theoretical perspective framework.

This work was built around a visual educational tool used in clinical practices by care providers to guide clinicians in discussing diabetes care, known as the Conversational Map. The Conversational Map incorporates the CDA 2013 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. My focus on patients’ experiences was informed by the approach consistent with critical ethnography with its attention paid to the insider perspective (Breda, 2013), where I also drew on concepts from Smith (2005) who encouraged to treated patients’ experiences not as discrete objects of interest, but as entry points into the broader web of social organization. Thus, in this work the individual respondent is not a source or topic of interest in and of herself/himself (Walby, 2007). In line with that perspective, I was interested in understanding the practices undertaken by people with severe mental illnesses in order to adhere to medically prescribed diabetes management. In doing so, I sought to go beyond individual level explanations of behavior to uncover the social contexts that play a role in shaping patients’ experiences with diabetes. This critical analysis of experiences of diabetes management among people with severe mental illnesses has also served to explore the (un)intended lived consequences of epidemiologically driven clinical recommendations and protocols for diabetes management.
Positioning: Diabetes as a Medical Problem

Chronic illnesses are often cited as posing a large public health threat, as they constitute 46% of global diseases and are responsible for 59% of deaths in Canada, tallying billions of dollars in annual medical expenditures (Coleman, Austin, Brach & Wagner, 2009; Dawson, Gomes, Gerstein, Blanchard & Kahler, 2002). The four main types of chronic illnesses include cancers, cardiovascular diseases, respiratory diseases, and diabetes, all of which are defined as conditions that are long-term, do not resolve spontaneously, and are rarely cured (World Health Organization, 2005). This work specifically focuses on diabetes mellitus type II (hereafter referred to as ‘diabetes’). It is viewed by clinicians and policy makers as having a major cost impact on public health expenditures in Canada with growing prevalence and mounting public costs, and as largely preventable by lifestyle change interventions (Fulton, Penney & Taft, 2001).

In Canada, mental illness is the second leading cause of human disability and premature death (Public Health Agency of Canada, 2015). People with severe mental illnesses experience greater adversities in their daily living, such as poverty, stigma, and discrimination, all contributing to higher level of unmet health needs within this population (Currie, Patterson, Moniruzzaman, McCandless & Somers, 2014). Studies have described people with severe mental illnesses as generally middle-aged, lacking in social support, often unemployed, homeless or under-housed, suffering from numerous comorbid conditions, and overall having higher levels of service utilization compared to the general population (Fleury, Grenier, Bamvita & Caron, 2011). Patients with mental illnesses incur over 30% more costs than other populations with other chronic conditions (de Oliveira, Cheng, Vigod, Rehm & Kurdyak, 2016; Rosella et al., 2014). Rosella and colleagues (2014) argue that those patients incurring highest costs are likely to be
older, have multiple chronic conditions, belong to a lower socio-economic status, and be physically inactive; these characteristics also overwhelmingly accompany severe mental illnesses. Therefore, given that patients with diabetes, as well as those with mental illnesses, already use a significant proportion of healthcare services, the combination of these two conditions may present a significant challenge for patients, clinicians, and policy makers.

**Rationale**

Research shows that people diagnosed with severe mental illnesses face complex barriers in accessing and utilizing health care services in general (Goldberg et al., 2007; Frayne et al., 2005; Mai, Holman, Sanfilippo, Emery & Preen, 2011; Pendlebury & Holt, 2008, 2010). Studies demonstrate that patients with complex needs, such as people with mental illness, experience ongoing difficulties in diabetes care (McKenzie, Hansson, Tuck & Luri, 2010). Most diabetes management activities take place in the everyday life of the diagnosed, away from the routine of the health care system (Kolling, Winkley & von Deden, 2010). However, patients continue to be expected to comply with complex medical regimens, developed by experts, through the practices of self-management.

In clinical practices, the chronic disease management model with its focus on patients’ self-management through compliance with pharmaceutical and lifestyle regimens, continues to be prevalent (Wagner, Austin & von Korff, 1996). This is despite recent critiques demonstrating poor evidence for the model efficacy (Boyd et al., 2005; Roberts & Bailey, 2011; Sidorov et al., 2002), cost effectiveness (Clar et al., 2010) questioning its relevance for populations with complex needs. Epidemiologists attribute these deficiencies to service delivery variations (Glasgow, Orleans, Wagner, Curry & Solberg, 2001; Lewis & Dixon, 2004), and inconsistency in how the model’s components are applied in clinical practices (Dennis et al., 2008). However,
social science scholars argue that service deficiencies in general can be better explained by the way social context interacts and forms the possibilities for everyday health practices (Campbell & Gregor, 2002; Deveau, 2008; Dickinson, 1999; Jones-Smith et al., 2013; Kontos, Miller & Mitchell, 2010; Mykhalovskiy, McCoy & Bresailer, 2004; O’Brien, Shuman, Barrios, Alos & Whiteaker, 2014). Scholars point out that the problem with statistical-based evaluation of patient self-management is not that it does not reflect reality but that it comprises a partial account. This incomplete understanding can result in the sustainment of ineffective or even harmful clinical practices (Eakin, Robertson, Poland, Coburn & Edwards, 1996; Gleeson, 1997; Oliver & Shapiro, 1990; Webster, 2009).

The problem of an incomplete understanding of diabetes self-care for people with serious mental illness forms the rationale and starting point for this inquiry. Therefore, this study seeks to understand diabetes management from the position of those diagnosed with severe mental illnesses as it is lived and experienced within the context of daily life.

**Study Objectives**

The specific study objectives were:

1. To explore the experiences of people diagnosed with severe mental illnesses and diabetes in relation to diabetes management as it is performed within their daily living contexts;

2. To locate diabetes management within broader relationships of social organization in order to facilitate a shift towards context-sensitive understanding of diabetes management; and,

3. To present a critical qualitative account of diabetes management in people with severe mental illnesses from the position of those diagnosed, in order to inform policies and practices
to improve health care services for people with severe mental illnesses specifically, and complex populations more generally.

**Thesis Organization**

The thesis has been organized as follows:

*Chapter One: Introduction.* This chapter introduces the study, locates my research interest within the broader topic of public health, and provides an overview of thesis organization.

*Chapter Two: Meet Brian.* In this chapter, I present a vignette describing a typical day of a patient diagnosed with diabetes and severe mental illness, in order to provide the reader with a reference point to return to when reading this thesis and assessing my conceptual interpretations.

*Chapter Three: Literature Review.* This chapter is a literature review of key fields that have informed this study, specifically, the social construction of diabetes through the biomedical lens, and alternative conceptualizations through social science perspectives. The purpose of this chapter is to analyze conceptually how the phenomenon of diabetes management is taken up in these key fields. This chapter provides important background to, and a conceptual understanding of, the theoretical positioning of this study.

*Chapter Four: Research Design.* This chapter identifies the theoretical framework upon which this research study is built, followed by the exploration of the research inquiry used, namely critical ethnography. I then provide a detailed discussion on ethical considerations I faced when conducted this study, including challenges around access. I continue with a detailed description of data sources and methods used in this research project, followed by discussion of my data
analysis. The chapter concludes with a discussion on the rigor of this project, specifically conceptual applicability, verification of knowledge claims through internal conceptual coherence, and critical subjectivity.

Chapter Five: Findings. A Roadmap of Diabetes Management. This chapter draws on ethnographic and interview-based data analyzed vis-a-vis the ‘Living with Diabetes Conversational Map’ (hereafter the Conversational Map). This map is a visual tool used by clinicians in their practices for people with severe mental illnesses and diabetes, which I discovered during my first on-site visit. The Conversational Map, a visual representation of dominant knowledge on diabetes care, portrays diabetes management by way of an illustrated roadmap which depicts a female patient through her diabetes journey. It clearly delineates both start and finish points, and indicates points of action and interest (e.g., food, medication taking, leisure activities, social interactions) in between (see Appendix I: The Conversational Map). Using the visual tool of the Conversational Map, I compare and contrast patients’ narrative accounts in relation to their diabetes management as lived against the diabetes management account presented in the Conversational Map. The chapter provides a thick description of patients’ experiences in relation to diabetes management practices, setting the grounds for the data analysis presented in a following chapter.

Chapter Six: Changing the Conversation. In this chapter I summarize the major findings of this study. I first map my findings to previous research to locate them within the broader framework of public health. I then follow with the main analysis, the re-drawing of the diabetes management road map. Specifically, I explore how the Conversational Map presents a rigid schematic model that reproduces a biomedical view of diabetes, where diabetes management is constructed through a linear-rational vision of health achieved through patients’ self-managed
compliance with pharmaceutical and lifestyle behavior recommendations. I then argue that contrary to this view, my ethnographic findings reveal a very different reality of patients’ self-management. I demonstrate how the experiences of patients with severe mental illnesses are shaped by fraught social circumstances that are not fully addressed by practice guidelines. Following that, I identify the strengths and limitations of this study and conclude with study implications.

Thesis Terminology

The terminology used in this thesis, first, reflects terms and themes commonly used in the medical literature on diabetes, such as diabetes mellitus, adherence, compliance, management, regulated, and so forth. Secondly, it includes terms used by social science researchers who problematize these medical understandings, such as problematic, social context, biomedical, organization of practices, social construction, multiple realities, and dominant knowledge (Coburn, 2006; Denzin & Lincoln, 1994; Smith, 1987, 2003, & 2005).

While I will reflexively explore my own social location in the care and study of people with severe mental illness in the section that follows, at this point I would like to emphasize that over the duration of this project, similarly to other scholars (Rogers & Pilgrim, 2014), I have learned that language can obscure both people and their health work I have therefore, along with terms such as respondents, individuals, people with mental illnesses, decided to use the term ‘patients’ to describe participants in my study who live with severe mental illnesses, rather than others commonly used in the mental health field, such as consumers, clients, survivors, or service users. I made this deliberate decision for several reasons. First, while I recognize that commonly used terms, such as clients, consumers, and survivors which were initially introduced
within the umbrella of stigma reduction strategies, following the expansion of market-influenced ideology and its penetration into health care system since the 1980s (Rogers & Pilgrim, 2014), are important vectors in promoting individual rights and choice, I found their use to be problematic when used to describe vulnerable populations. Those terms conceptualize individuals as logical, rational, and resource-rich consumers engaged in personal choices, where these choices are readily available and accessible. Such a context is overwhelmingly inconsistent with the circumstances of the vast majority of people diagnosed with severe mental illnesses I came across in this doctoral work and in my clinical practice.

I believe the term ‘patient,’ while imperfect, captures something important about the social location of those afflicted with illness (“Patient”, n.d., para. 2& 4). According to the Merriam-Webster dictionary, the term “patient” comes from the Latin verb "patior" meaning to suffer in the sense of feeling pain, that is physical, but also emotional, and, as is my focus, social (“Patient”, n.d., para. 4). While the conceptualization of individuals diagnosed with medical conditions as patients has been recently critiqued in an attempt to change its perceived passivity (Aneshensel, Phelan & Bierman, 2013), my choice of continuing to use the term ‘patient’ within the conceptualization of a ‘sufferer’ is thoughtful.

In naming my participants with severe mental illnesses as patients, I want to achieve two goals. First, I want to focus on a definition of a patient as someone who is bearing or enduring difficulties (“Patient”, n.d., para.4), and I want to bring these people, and their difficulties, into view. Secondly, I want to separate my work from those that take a managerial understanding of the individual as a consumer with an emphasis on free will, individual choices, and value-for-money philosophy. My intention is to focus on individuals with severe mental illnesses engaged
in diabetes management as human beings living within particular and complex medical, psychiatric and social contexts, and in need of health and social care.
My Standpoint

I came into this project with multiple insights and perspectives on the phenomenon of diabetes management, gleaned through having worked as a psychiatrist with people diagnosed with severe mental illnesses for over ten years. I also worked as a clinical social worker at the inpatient unit of one of the major psychiatric facilities in North America, and engaged in graduate work as a PhD student in a School of Public Health in a major urban university. Thus, my particular social position afforded me several privileges in relation to patients whose lives I became interested in studying, as well as created access for me to complete my studies. Because of this significant privilege, it is particularly important for me to position myself reflexively in this research so that my own assumptions are transparent.

As a clinician trained in biomedical sciences, I was expected to follow a particular set of clinical practices in my daily work. I am encouraged to act on what is defined as “best practices,” and outlined by clinical guidelines or/and regulations, in my work with patients and during the process of making clinical decisions. For most of my clinician career I did not question these definitions of evidence and best practice. Yet as a student in a doctoral program in public health, I was invited to challenge my assumptions and apply different theoretical lenses in order to develop a comprehensive understanding of any phenomenon of interest. The impetus for this work initially emerged from the internal discord I experienced while working as a hospital social worker at an inpatient unit that treated people with severe mental illnesses and diabetes.

My work as an inpatient clinical social worker at a major psychiatric hospital took place from September 2010 to January 2011. During that time, I engaged in numerous interactions with patients and their families in relation to diabetes care. This social work clinical role allowed me to expand my specialized training in medical science. Through a focus on the social realities of
my patients, including poverty, financial constraints, and lack of housing, I recognized that my previous medical lens oftentimes obstructed my view of patients lived contexts and their struggles over diabetes management rather than clarified it. The contradiction left me puzzled, and in search of answers.

My doctoral study provided me with the opportunity to understand that all research is inherently subjective, and that all researchers have a particular world-view, which underpins and shapes their projects and findings (Green & Thorogood, 2007; Guba & Lincoln, 1994, 2005). My doctoral program, with its focus on different theoretical perspectives, led me to discover the work of social science scholars and different perspectives for conceptualizing and understanding medical endeavors, all of which I had not yet considered within my taken-for-granted worldview. This understanding came neither quickly nor easily, and it was marked by a continuous struggle through years of graduate school. As a clinician trained and socialized into a paradigm valuing an objective and unified reality, it was difficult to accept that knowledge, including knowledge from the medical field, is constructed within a particular sociohistorical continuum. It emphasizes the socially interactive basis through which all knowledge, both everyday and medical, is constructed and reconstructed (Ward, Hoare & Gott, 2015). Similar to Ward’s (2015) experience, who was a nurse by training, my post-positivist psychiatric career oriented me towards testing, verification, and prediction of hypotheses in exploring causal relationships among variables when approaching diabetes care in people with mental illnesses. It steered me away from the explicit political stance of many social science theorists. Understanding reality through lens of social science pushed me to question my skills, knowledge, and abilities; which initially, greatly destabilized my own assumptions. As I progressed through my graduate studies, and familiarized myself with the work of other clinicians engaged in social science research, I gained deeper insight into my ongoing struggle.
Similar to other scholars, I now questioned the notion of a researcher and/or clinician as a blank slate and an impartial observer. This allowed me to pose new questions regarding the authoritative knowledge I had once relied on, and to use different theoretical lenses to gain different insights.

In retrospect, I can report that this epistemological struggle proved fruitful. Reconciling a positivist history with social science views has enabled me to see that different versions of reality co-exist and are valid. It has also given me the invitation to approach my topic of interest from a different standpoint. I now understand that all knowledge is rooted in social, political, historic, and material contexts, and that meaning is contextually bound (Bisallion & Rankin, 2013). This perspective guided me to reconsider my ‘expert’ social location in psychiatry. Resolving my epistemological struggle in this way opened up new ways of knowing, thinking, and speaking on the subject of the everyday experiences of people with diabetes and serious mental illness.

To summarize, this chapter introduced the focus and organizational structure of this thesis. As a point of departure, this chapter also reflexively introduced my standpoint evolution, and a rationale for shifting research attention away from the perspective of biomedical experts to the standpoint of patients experiencing diabetes and serious mental illness. In the next chapter I introduce the hypothetical composite of one such patient, whom I have named ‘Brian’, and the everyday complexities he encounters in his diabetes management.
Chapter 2: Meet Brian

Introduction

In this chapter I present a vignette of a patient diagnosed with mental illness and diabetes, and I call him Brian. Brian is not a single individual but rather a composite, an integration of participants I have interviewed, patients I have observed, and clinical practices to which I was exposed over the span of my career as a clinician. You can imagine Brian as a collage of snapshots, his face from one photograph, his arm from another. While each part represents something real and the collection blends meaningfully, I have imagined the relationships between the parts. Of course, there are also significant limitations to this collage, as I am not able to incorporate particularities of race, gender, and age, all of which are influential attributes to one’s existence. My aim with presenting this vignette is twofold. First, I want to provide a reader with a point of reference to come back to when reading patients’ narratives and my analysis. Second, I made the decision to construct this composite, because I believe it enables me to best describe the spectrum of experience of people with severe mental illnesses and diabetes.

Locating Brian

Brian is a 55-year-old single man who was diagnosed with schizophrenia over twenty years ago. He has had numerous inpatient hospitalizations, but has managed to avoid hospital admissions for the last five years, a stability which his caseworker attributes to him being managed well in the community. His caseworker, a nurse, was assigned to him after his last hospital discharge. She is responsible for Brian’s case, meaning that she provides some help with his housing,
finances, and numerous appointments through advice, negotiation, and reminders when needed. Brian is told to see her once a week even during times when he does not need anything; which is referred to as a ‘check-in’. The purpose of a check-in is to have a brief conversation so caseworker knows whether there is any change in his psychiatric symptoms, to make sure Brian continues to take his medications, and completes his blood work every three months or so.

Brian lives in a boarding house. It is an older three-story building located in a central urban area, where he shares this house with ten other tenants. Brian has his own room and a small washroom. There is a housing worker present on premises around the clock, and meals are provided. Brian has been living in this house for over two years now, after his previous boarding home of seven years was closed. His previous place was located in the west end, near a lake and a park, and in a quieter area. His current place is located near a major road intersection, and is busy and loud at times. However, Brian’s housing application included a restricted number of options, and as this home was the closest to the community agencies and services he attends, Brian chose it for its convenience. Usually, Brian does not like changes, as it is hard for him to get to know new people. He felt sad he had to leave the previous boarding house, and it took him a while to adjust to this new one. Although he felt anxious, and his symptoms worsened during transition, he still felt grateful for having a roof over his head, as he had previously lived on the streets. Brian is unemployed, and fully relies on governmental assistance, called Ontario Disability Support Program (ODSP), from which he receives $596 monthly. Because he lives in a boarding home, his rent and board expenses are paid directly to the property owner, which leaves him $100-120 each month to cover his transportation costs, clothing, food, hygiene products, and entertainment. He had been receiving an additional $100 for his diabetes, but he lost that supplement when he became too sick to attend appointments. His caseworker is currently trying to help him to re-apply.
Brian visits his psychiatrist regularly. He was diagnosed with diabetes two years ago following a routine blood test. His psychiatrist referred him to a family physician by forwarding Brian’s information to a nearby clinic and telling Brian to go there. Brian received a call from the clinic to attend an appointment, which he did. Since then he comes to the clinic every four months to do his blood work and to attend an educational group, which is called the ‘metabolic clinic.’ Other patients have also been diagnosed with some type of mental illness, and similarly to Brian, are learning how to deal with their diabetes.

One Day from Brian’s Life

Today is “appointment Thursday” for Brian, when he is expected to attend the metabolic clinic where his family practitioner works, see his nurse, and participate in a diabetes care group. The clinic’s secretary called him yesterday, and reminded him about his appointment, so he would not miss it.

Brian usually wakes up early because of ongoing insomnia, which might be the result of his evening medications, or stress, or when the voices he hears are getting worse. Over the years, he has adjusted to his early wakening, and has actually started to enjoy the early morning quiet time to himself in a house that is usually loud and hectic. Typically, Brian fixes himself some coffee with milk and sugar, even though he knows sugar is “bad for you.” But he prides himself in being a ‘server’ in a house, the one to serve others with a cup of coffee and tea, and he enjoys a process of making a coffee pot, and preparing a drink. On “appointment Thursday,” Brian is not able to do this or much else, as he has been instructed by his medical team not to eat anything before he sees his nurse for the blood test. On any day, other than appointment Thursday, Brian would take breakfast, which is provided by the housing staff and is usually served in the common kitchen area. Breakfast might consist of toast, cereal with milk, or
muffins if there was a donation from the nearby bakery the previous night. At times, Brian would prefer to eat something else for breakfast, such as fresh fruit or yogurt, but the housing manager told him that “money are tight’ and there are a lot of other people in his house who need to be served as well. Typically, Brian starts his morning with “checking his sugars.” To do so, he uses the glucometer device given by his nurse, pokes his finger, and reads the number that shows up on the small screen. The nurse and the pharmacist showed him how to do that. He then records the number to tell his housing worker later, who documents it in a notebook kept downstairs. Brian was told by his nurse the number he is supposed to aim for, and it is usually between seven and nine. Brian’s medications, as with the medications of other tenants, are stored in a locked cabinet in the manager’s office. Because of the boarding home rules, the housing worker is responsible for giving Brian his diabetes pill, which is called Metformin, every morning after he finishes his breakfast.

Today Brian is expected to attend the clinic. It is within a walking distance, but he injured his knee recently, and today he must take a bus or a streetcar. Transportation cost is a challenge in general, and he has to be mindful of his spending given his limited budget. A return trip usually costs him over $6 and, at times, he has several different places to go to on the same day. He volunteers at a food bank and at two community centers, which are located several kilometers away from his boarding home. He volunteers at both because he likes to be around other people and to help, and because he can have a free dinner in exchange for volunteering. Sometimes they also may cover some of his transportation costs, which is important for Brian as it helps him to save money on something else. Brian tries to walk everywhere as much as he can, and he uses walking as an exercise. It becomes a challenge at times as his arthritis recently worsened, making it hard for him to walk, and the recent snowy weather kept him housebound for the majority of the week. He has sometimes snuck through the back doors on buses and trains to
avoid paying the fare, but he does not do this often as he tries to “stay away from trouble.” Brian is always early for his appointment, and usually waits outside of the clinic with several other patients. As soon as the receptionist is in, she allows patients to wait inside, and he sits very quietly in the waiting area until the nurse calls his name. It’s the same routine each time. First, the nurse begins by asking him how he is doing. Then she measures his blood pressure, weight, and the circumference of his waist. She enters all of this information into the computer. Finally, she takes a blood sample, a particularly painful procedure for Brian, since he is afraid of needles and his veins are hard to find, and for the past three weeks, he has undergone other blood tests his psychiatrist mandated. The nurse tells Brian this is to help see exactly what is going on with his blood sugar. After his meeting with the nurse, he is sent to a large communal room with other patients to have breakfast, which includes juice, a banana, and oatmeal. Brian usually likes this part the most, as there is no charge for it, and he can chat with other people. Although Brian is ready to go home, he has to stay for the group meeting, where a nurse discusses diabetes, food, and exercise. There is the Conversational Map, which is placed on the table, and the nurse often points to it often while talking to draw everybody’s attention to specific aspects on it. The illustrated map is colorful, and Brian tries to follow along with the nurse’s pointing and explanations, but he rarely participates unless a nurse directly asks him a question. He is often unsure about how useful the map is to him, as many of the food options pictured on it are not served at his boarding home, and he already follows the clinic’s instructions to use a glucometer. Group lasts for an hour, and by the end of it, everybody is a bit anxious and restless to leave. Brian feels tired, and there is still the trip back, and other errands he needs to complete. On other afternoons, Brian may venture to his preferred food bank to pick up some groceries or go meet his friends at Coffee Time (name of a coffee shop), volunteer at the community center, or visit the other community center where he pays only $1 for dinner. These activities are hard to complete on his appointment Thursdays as his energy is often low and feels tired, so instead
he usually goes back to his house, watches television, and talks to others while he waits for dinner to be served. He might try to go to sleep earlier, yet this is often disrupted by the excessive noise of people around the house. Tomorrow is another day, with other chores, appointments, visits, and struggles.

Summary

Brian’s story is a fairly typical case I have observed in my clinical practices with people living with mental illnesses and diabetes. Brian’s medical story is clear and familiar to me as a clinician. It demonstrates diabetes as a set of medically prioritized problems with specifically medical solutions, such as focusing on blood glucose levels, weight, diet, exercise, medication taking, and complying with clinical appointments. However, this vignette also tells a different story, a story which illustrates how Brian undertakes the complex and consistent work of managing those problems while also suffering from mental illness, living in poverty, and relying on government assistance for survival. His social story demonstrates the points at which social and material complexities converge, and may have consequences for diabetes self-care.

In the next section I provide the reader with an overview of literature pertinent to examining the management of diabetes by people diagnosed with serious and persistent mental illnesses, in order to situate the conceptual and theoretical positioning of this study.
Chapter 3: Literature Review

Introduction

This chapter provides a summary of the literature in relation to the phenomenon of diabetes and diabetes management in people diagnosed with severe mental illnesses, and explores the assumptions that organize research and clinical practices in this area. The goal of this literature review is to describe the strengths and gaps in current empirical work, and to establish the rationale for this doctoral project. The overarching questions I posed when reading this literature were: how is diabetes self-management described in the literature; and, how might this be relevant for people with mental illness? The literature on both diabetes and several mental illnesses is vast. Therefore, I organized the literature into three distinct domains that were most relevant for my thesis: epidemiological data on which clinical practices are based; psycho-social literature that explores health care management through a patient perspective; and finally, social science research where my work is currently situated.

Search Strategy

In undertaking this literature review I first searched the following databases: Medline, PubMed, OVID, and ProQuest using the search terms, such as diabetes, diabetes type II, mental illness, schizophrenia, and depression. Throughout my search I identified three major literature domains. The first is aligned with epidemiological science. It comprises an extensive literature dedicated to the topics of prevalence, morbidity and mortality, exploration of cause-and-effects relationships; followed by equally substantial amount of experimental interventionist research focusing on behaviors around diabetes and a variety of effectiveness assessments on outcomes and interventions, where conclusions are drawn through the employment of statistical methods
of analysis. The second literature domain is that of the psycho-social. It is dedicated to the exploration of patients’ experiences, specifically individual attitudes, beliefs, and behaviors, as well as emotional responses and coping mechanisms. It views diabetes management in terms of psychological particularities and behavior, where interventions are aimed to understand and to correct deficiencies. Some psycho-social research is dedicated to access, care utilization, and societal adversities, and examines social determinants of health (e.g., poverty, racial minority status, etc.) in relation to patient experience.

Reading within these two domains, I identified several articles discussing different perspectives, and talking about illness and illnesses experiences in terms of social construction of knowledge, prompting me to expand my literature search to the social sciences. In order to do that, I added the Sociological Abstracts database to my previous searches, using a broad set of key words such as diabetes, mental illness, and experiences. Insights identified from this third domain comprise a section on the social science literature in my literature review.

**Conceptual Appraisal**

In reading the three literatures identified, I became more familiar with their perspectives. I treated them as empirical data. In consequence, they helped me to understand how diabetes management is situated as a problem, and assisted me in identifying gaps that I wanted to address in my research.

I found that the epidemiological literature, most prevalent in the diabetes management field, focuses attention on biological, behavioral, and environmental aspects of diabetes and diabetes management, and on a variety of interventions to target the abovementioned aspects. In the next section I begin with the exploration of epidemiological literature in the field of diabetes
management in order to demonstrate how it obscures social context as an important factor in developing both the illness and the ways of experiencing it. Building on this, I move into the social science literature on illness, which argues for the importance of paying attention to how social context determines and shapes personal experiences of patients, and how this context, in turn, reflects wider social and historic milieus.

This conceptual appraisal provides the background and conceptual rationale to the theoretical positioning of this study. It justifies the need for this doctoral project, and its use of critical ethnographic inquiry, as a means to reveal new insights for the understanding of diabetes management in people with severe mental illnesses.

Epidemiological Literature on Diabetes Management

The epidemiological research on diabetes and diabetes management focuses on the exploration of causes, effects, and patterns with the use of quantitative methods and statistical analysis. This domain is represented by two major foci. First, the causation literature, which is dedicated to the exploration of the genetic and biological (e.g., inherited), along with psychological (e.g., behavioral) and socio-environmental (e.g., psycho-social) causes of diabetes. Second, I reviewed the intervention literature. Informed by causation research, this literature aims to explore diabetes management through a particular emphasis on the self-management of diabetes, and understanding and addressing patient noncompliance with provider recommendations.
Causation Literature on Diabetes in the Presence of Severe Mental Illnesses

Causation literature assumes cause-effect relationships and aims to identify effective treatment and prevention strategies. Within the context of diabetes in the presence of severe mental illnesses, this literature domain characterizes diabetes as inherited or as acquired. For the purposes of this thesis I have focused on type II diabetes which is acquired, as this is the type most likely to affect those with mental illness, and also is considered modifiable through self-management. In medical terms, diabetes is defined as a serious and chronic endocrine disorder characterized by a high level of blood glucose, known as hyperglycemia, because of defects in insulin secretion and/or insulin action (Doucet & Beatty, 2010). Severe mental illnesses are defined as a long-term (over two years) psychiatric brain disorder(s), marked by significant functional limitations, and requiring ongoing psycho-pharmacological therapy (Gibson, Carek & Sullivan, 2011; Ruggeri, Leese, Thornicroff, Bisoffi & Tansella, 2000).

Diabetes as Inherited

Studies informed by epigenetics identified the involvement of particular genes, and endocrine disbalance as playing role in development of diabetes in people with severe mental illnesses. For example, Thakore et al.’s (2002) cross-sectional study showed that drug-naïve individuals with psychosis had three times more intra-abdominal fat compared to healthy controls, arguing that higher rates of diabetes in this population could be attributed to an altered neuroendocrine system, specifically higher plasma cortisol levels. In line with that, Ryan et al.’s (2004) cross-sectional study demonstrated that drug-naïve individuals with psychosis had more than 15% impaired fasting glucose levels compared to healthy controls, suggesting people with mental
illnesses are predisposed to diabetes, and medication may not play as vital a role as previously argued (Clark, 2004; Jin, Meyer & Jeste, 2004). Statistical evidence for a direct genetic link in people with mental illnesses is further argued by Gough and O’Donovan (2005), who demonstrated that a higher number of people with severe mental illnesses (17-50%) had a first-degree relative with type II diabetes. This suggests genetic inheritance as a potential explanation for higher levels of diabetes in people with severe mental illnesses. These findings linking higher diabetes rates to genetic factors have also been supported by the study by Spelman and colleagues (2007), and the systemic review by Bushe and Leonard (2007). This literature is premised on the understanding of the biological science of disease, where abnormality is attributed to the individual, and is located within the locus of biology.

**Diabetes as Acquired**

The second strand of causation literature views diabetes as a disease, which can be acquired either through individual behaviors, or through iatrogenesis (Holt & Peveler, 2006; Strassnig, Awerbuck & Ganguli, 2013), which is considered a consequence of psychotropic medications, with individual and environmental aspects act as mediating determinants.

Causation research describes diabetes as associated with unhealthy behaviors, often referred to as lifestyle choices, such as poor diet, low levels of physical activity, and substance use (Scott & Hoppell, 2011). The exploration of behavioral factors in the literature occupies a larger niche than the literature dedicated to the exploration of diabetes as a result of iatrogenesis, as psychiatric medications are viewed as an essential part of psychiatric treatment and behavioral aspects are viewed as potentially modifiable (Pendlebury & Holt, 2010).
Behavioral Literature

The literature on diabetes as a consequence of individual behavior choices in people with severe mental illnesses echoes the literature on diabetes and chronic illnesses across other populations, such as chronic obstructive pulmonary disease (Bourbeau, Nault & Dang-Tan, 2004), coronary heart disease (Stampfer, Hu, Manson, Rimm & Willett, 2000), and chronic kidney disease (Stengel, Tarver–Carr, Powe, Eberhardt & Brancati, 2003). In diabetes, the main aspects discussed in the literature are dietary choices, weight control, low levels of physical activity, and behaviors around medication compliance. People with severe mental illnesses have been shown to have diets containing higher amounts of fats and refined sugar, and inadequate fruit and vegetable intake (Brown, Birtwistle, Roe & Thompson, 1999; McCreadie et al., 1998). In people with severe mental illnesses, similar to those from general population, being overweight has also been linked to higher diabetes rates as demonstrated by Ratliff and colleagues (2013). Janney and colleagues’ (2013) randomized control trial of 252 community-dwelling patients found that low levels of physical activity in this population are also linked to higher levels of diabetes and overall lower quality of life. They found that over 81% of the participants diagnosed with severe mental illnesses spend approximately 12 hours or more daily than 80% of their monitoring time engaging in sedentary behaviors, compared to previously reported in adult population-based studies in the US indicating around 57% of monitoring time (Janney et al., 2013). This literature suggests the development of diabetes is a result of individual poor choices (see for example, Bushe & Leonard, 2007 systematic review), resulting in mounting public health spending (Hutter, Schnurr & Baumeister, 2010). Based on this understanding, many of the negative consequences of diabetes are viewed as modifiable through individual behavior choices, an understanding which currently informs a variety of behavioral and psychosocial interventions,
such as weight reduction through diet and increased physical activity (Janney et al., 2013; Strassnig, Brar & Ganguli, 2003a, 2003b).

Psychosocial Literature

The field of psychosocial research initially developed within the field of social epidemiology in mid 1990s, and has gained increased popularity over the past decade (Martikainen, Bartley & Lahelma, 2002). This research moves beyond the biomedical to suggest that understanding diabetes and diabetes management should include an understanding of environmental, social, and cultural factors which affects the daily contexts of a person’s life, and shapes their behaviors and their opportunities (Richmond, 1998). However, this literature, still focuses on patients’ individual perspectives, such as their beliefs and attitudes in relation to diabetes and diabetes management, and their responses, such as emotional reactions and coping strategies, along with environmental aspects, such as patients’ environment, social support, and patients’ locus of control.

Psychological Aspects

In the psychosocial literature on illness perspectives, many have recognized that the inception of an illness leads patients and those close to them to ask questions about what is happening, why it is happening, and what can be done. This “quest for meaning – “Why me? Why now?” – has been identified in studies of the significance of illness and is central to phenomenological inquiries into the illness experience itself” (Pierret, 2003, p. 8). As such, subjective perspectives of those diagnosed are recognized as wide-ranging and diverse. Several scholars have offered a variety of classifications to explain why and how subjective perspectives on chronic illness differ (Kelleher, 1988; Ockleford, Shaw, Willars & Dixon-Woods, 2008).
Kelleher (1988) in his observational study, conceptualized subjective experiences of those diagnosed with diabetes based on whether or not they complied with medical recommendations, categorizing patients into categories of ‘copers,’ ‘normalizers,’ and ‘agonizers.’ Within these categories, those who aligned their subjective experiences with providers’ understanding, specifically copers and normalizers, were linked to better clinical outcomes, compared to those who had challenges accepting their diagnosis, such as agonizers. The authors concluded that personal perceptions and beliefs around illness impact patients’ further actions in dealing with chronic condition. Similarly, Ockleford and colleagues (2008), used semi-structured interviews of 36 adult patients to examine patients’ subjective experiences around self-management and behaviors in relation to medical recommendations. They categorized patients as ‘accepters,’ ‘identity accepters but consequences resisters,’ ‘identity resisters, consequences accepters,’ and ‘resisters,’ and demonstrated that patients’ decisions around their diabetes and its management are informed by their attitudes towards it.

This literature expands our knowledge of diabetes and its management, moving towards an understanding of its subjective components, such as personal beliefs, attitudes, and reactions, where personal actions are understood within the context of meaning-making. However, it continues to locate diabetes within the individual psychological sphere, and pays limited attention to how personal subjective experiences are developed within, and altered by, particular environments.

Environmental Aspects in Psychosocial Literature

Some psycho-social literature goes beyond individual behavior to investigate relationships in the social environment, which includes such dimensions as social support. Several important topics were identified within this literature domain that are directly relevant to the topic of diabetes
management in severe mental illnesses. For example, poverty has been closely interconnected to diabetes and challenges in diabetes management, with studies linking low socioeconomic status and associated stress to physical changes in one’s body that result in higher diabetes rates (El-Mallakh, 2007; Tamayo, Herder & Rathmann, 2010).

Lawton and colleagues’ (2005) qualitative study of 32 British South Asians diagnosed with diabetes type two demonstrated the importance of understanding how social rules and cultural expectations influence personal behaviors around diabetes and diabetes management. They showed that the prioritization of obligations to kin, restrictions on women leaving the home, lack of socialization into sports, and personal beliefs (e.g., that exercise potentially weakened their bodies in nonreversible ways) all affected personal decisions around diabetes and diabetes management. The authors also suggested that the adoption of expertly defined recommendations could unintentionally result in alienation from their culture and communities, ultimately causing noncompliance and withdrawal from clinical care. Similarly, Mendenhall and colleagues (2012) in their qualitative analysis of the social experiences of individuals with diabetes living in Delhi, India alluded to the relationship of diabetes to social, psychological, and cultural domains. The authors found that few people held similar diabetic beliefs to the biomedical explanatory model; instead, participants attributed diabetic causes to social and spiritual aspects. For example, they described how patients attributed feelings of tension to work responsibilities, which was frequently reported by participants with higher socio-economic status; or feelings of stress associated with children’s future, financial security, and family dynamic, as reported by those with low-income. Other environmental factors, such as patient-provider communication, have also been demonstrated as an important environmental aspect affecting decision-making process in people with diabetes. It has also been suggested that a providers’ decision making related to patient care closely relies on providers’ perceptions of the social, cognitive and psychological
characteristics of their patients, including patients’ intellectual abilities, motivation, quality of
social support, lifestyle, anxiety levels and style of interaction (Lutfey et al., 2008; Skovlund &
Peyrot, 2005).

Psycho-social understanding of diabetes and its management brings attention to patients’
individual accounts of illness experiences and their social contexts, moving away from the
medical understanding of diabetes as a purely physiological illness. Here, illness experiences are
understood as heterogeneous, comprising multiple meanings, which develop through the
interaction of an individual and a social environment. Psycho-social understandings importantly
validate patients’ subjective experiences, and place those experiences at the center of research
and clinical practices, recognizing patients as active participants in decision-making. The
psycho-social literature provides a foundation for moving forward in these directions, as a more
active patient can be a more empowered patient, and a patient understood within his/her
environment of living may be a less stigmatized one. Using this lens, attention is redirected from
individual actions towards the understanding of how these actions reflect the environment in
which the patient is embedded.

However, while this perspective acknowledges a dynamic relationship between patient
experience as an interaction between individual, social, and cultural environments, it tends to
overlook the social and historic organization of practices and development of these experiences
themselves. Psychosocial interpretations continue to accept that patients are exclusively
responsible for their behaviors, and clinicians are expected to decide upon a course of treatment
on the basis of scientific criteria alone. Alternatively, critical social scientists suggest that
differences in personal experiences should be understood within a particular social and historic
context, where this context manifests in illness experiences (Crossley, 1998; Daly & McDonald,
1992; Gomersall, Madill & Summers, 2011). While recognizing personal experiences, diabetes
research informed by the psycho-social perspective lacks an understanding of how broader aspects of societal structure shape and form these individual experiences, and how these societal structures are developed within a particular social, political, and historic context, aspects which are better uncovered by critical social science (Wilson, 2000).

**Intervention Literature on Diabetes**

Understanding diabetes within biological and behavioral frameworks has informed the development of intervention literature. Interventionist research on diabetes focuses on behavior modifications through *self-management*, and emphasizes and addresses noncompliance, when recommendations for self-management or treatments are not followed.

**The Concept of Self-Management**

Since the 1990’s the idea that patients should be involved in managing their own disease has been popularized in clinical practice through the self-management literature. Wagner’s Chronic Care Model framework (1996) has been instrumental to this movement and there has been widespread adoption of his approach. This model was developed to enable patients to “better care for their illness” (Norris et al., 2002, p.300) by identifying goals and plans, and practicing self-determination (Von Korff, Gruman, Schaefer, Curry & Wagner, 1997). Self-management models are claimed to be centered on the client’s perspective, anticipating a patient’s active involvement in her or his own care, which is also expected to shift professional-patient relations towards collaboration and mutual agreement on goals (Von Korff et al., 1997). The main self-management activities identified in the literature include surveillance of one’s weight through proper diet and regular physical activity, and the following of expert recommendations around medical care.
In the field of diabetes more broadly and diabetes management in severe mental illnesses specifically, increased weight has been depicted as a common issue for people (Citrome & Vreeland, 2008). Therefore, self-managing one’s weight is an important focus in interventionist practices. Findings from the general diabetes literature, such as Orozco et al.’s (2008) meta-review, demonstrate that interventions targeting exercise plus diet reduce the risk of diabetes compared with standard recommendations, as these interventions have favorable effects on weight and body mass index reduction, waist-to-hip ratio, and waist circumference. Building on findings informed by diabetes research from the general population, interventionist research for people with severe mental illnesses also focuses on interventions targeting weight, diet, and low level of physical activity. Some studies demonstrate that interventions targeting dietary choices and physical activity levels in people with severe mental illnesses are effective in addressing weight reduction. For example, Brar and colleagues (2005) conducted a 14-week randomized trial evaluating effects of a group-based behavioral treatment for weight loss in 72 obese patients with severe mental illnesses, and demonstrated that structured interventions can effectively reduce weight in patients with psychotic illnesses. Similarly, Daumitt and colleagues (2013) demonstrated the effectiveness of an 18-month behavioral weight-loss intervention for adults with severe mental illnesses. Druss and colleagues (2010), in their peer-led intervention to improve self-management around behavioral choices in people with severe mental illnesses, also argued that increasing knowledge and support around diabetes interventions had a positive impact on patients’ facilitation of self-management, and potentially was beneficial to improve patients’ health. Sajatovic and colleagues (2011) demonstrated that the use of peer-educators with serious mental illness and diabetes to teach and model self-management was effective for engaging patients in self-management and lifestyle behaviors around weight control. These studies dedicated to the exploration of self-management in relation to weight surveillance operate on the deterministic principle that the patient alone is responsible for success in
behavioral modifications. This understanding implies that compliance failures may, at least in part, be due to personal deficiency in decision-making processes around treatment recommendations.

However, some scholars argue that the existing self-management practices when applied to populations with complex needs “invoke an individualistic concept of the self that is rational and capable of exerting control over behavior in the interests of a healthy body” (Gomersall et al., 2011, p.865). In line with this, recent research from social science perspective adopts different lenses for interpreting difficulties with self-management, pointing out that poorer health in this population can be associated with overall disparities in healthcare provision, pervasive stigma associated with mental illness, and the consequences of psychiatric treatment (Lawrence & Kisely, 2010). Social science scholars questioned self-management deterministic views by demonstrating significant differences in how patients and providers understand diabetes and care associated with it. For example, Fitzgerald and colleagues (2008) demonstrated that patients with diabetes experience and give meaning to diabetes within a personal sociocultural world, where diabetes concepts are understood within the domain relevant to each individual (e.g., having a wound which is not healed). For providers, diabetes concepts and terms were more likely to have a more direct and precise meaning related to diabetes task performance, such as increased levels of glycated hemoglobin as a determinant of a poor glycemic control (Fitzgerald et al., 2008). The authors demonstrated that patient self-management is determined by one’s lived environment, where individual behavior reflects subjective experience in relation to what is considered relevant to a particular individual within particular circumstances.

These differences in subjective perspectives are important. By definition, self-management is performed within real life circumstances, and particular living contexts. Nevertheless, lived
circumstances and context are often absent from routine diabetes management clinical practices. Medical and behavioral views of diabetes, and diabetes management, continue to monopolize clinical practices and regulatory policies with their perspectives of unified knowledge and objectivity, resulting in one-size-fits-all strategies. In medical research, this understanding of self-management limits its applicability to populations with complex needs, as it obscures our understanding of individuals with unique experiences that cannot be standardized.

The Concept of Compliance

Developing knowledge about the factors that influence individual responses to provider recommendations is important, as studies indicate that lack of compliance with prescribed regimes in diabetes management is highly detrimental. For example, it is associated with higher levels of diabetes medical complications, poorer quality of life (Chiverton, Lindley, Tortoretti & Plum, 2007; Fulton et al., 2001), and higher health care systems expenditures for this population (Breton et al., 2013; Strassing, Brar & Ganguli, 2012). The concept of compliance, often used interchangeably with adherence, is commonly defined as the extent to which a person’s behavior coincides with expert recommendations (Brown & Bussell, 2011). In this particular literature domain the literature converges from two distinct streams: compliance literature informed by psychiatry field research, and chronic illnesses literature.

In the psychiatry literature, the topic of noncompliance is most often approached from the perspectives of medical providers. Nose and colleagues’ (2003) systematic review of 103 studies on rates of patients with psychotic illnesses who fail to adhere to treatment regimes reported the estimate range of nonadherence ranging from 24 to 90%, with a mean level of nonadherence of approximately 60%, concluding that on average 1 in 4 patients fail to comply with their prescription and treatment regimes. This level of noncompliance in people with severe
mental illnesses appears to be much higher compared to those of the general population, where reported rates are around of 24.8%, as demonstrated by DiMatteo (2004) in a large systematic review of 569 studies on compliance conducted over the span of 50 years. To date, no one explanation exists to clarify the higher noncompliance rates among people with severe mental illnesses. However, having a mental illness is cited by some as a contributory factor, as it may compromise one’s ability to judge the usefulness of the proposed treatment due to exposure to larger range of medication side effects, overall higher complexity of the regime, and poor communication between patients and providers (Brown & Gray, 2015; Vermeire, Hearnshaw, Van Royen & Denekens, 2001). On one hand, many medical experts suggest that noncompliance is a consequence of compromised insight into illness, namely that psychiatric symptoms such as delusions, hallucinations, and associating deficiency result from executive functioning impairment. and the consequent inability to retain and process information renders patients as incapable of understanding they are ill (Shrivastava, Johnston & Bureau, 2012). On the other hand, patients advocacy groups challenge this view, claiming that it discounts patient agency, and labels patients with severe mental illnesses as inherently incapable and problematic (Entwistle et al., 2010). Therefore, in the context of severe mental illnesses, the discussion of individual capacity in relation to patients’ ability to comply with expert advice remains controversial.

In the field of chronic illnesses, the idea that noncompliance cannot be solely explained as a result of volitional behavior is supported by literature that looks at specific populations. For example, some literature suggests that in general diabetes care support (e.g., medical, social network) is more readily available than for those with severe mental illnesses (Dailey, Kim & Lian, 2001). Yet it is still challenging to achieve for many, such as ethnic minorities (Sarkar, Fisher & Schillinger, 2006; Schectman, Nadkarni & Voss, 2002), and people with low socio-
economic status (Bains & Egede, 2011). In these studies, scholars acknowledge the limitations of approaching both self-management and noncompliance from a deterministic position of individual behavior, and recognize that managing one’s chronic condition is demanding and challenging. Knowledge of optimal self-care is necessary, but it is not sufficient (Ziguras, Klimidis, Lambert & Jackson, 2001). Therefore, new research has called into question the understanding of diabetes management as solely located within pathology and behavior, moving towards a psycho-social understanding, where individual health behavior is viewed as influenced by one’s social, economic, cultural, and physical environments (Sabourin & Pursley, 2013; Young & Unachukwu, 2012).

Summary

This literature overview on diabetes and diabetes management in relation to those with severe mental illnesses identified overrepresentation of epidemiology-informed studies dedicated to causational and interventional research. In this literature, the biological/physiological understanding of diabetes is prevalent, which then subsequently leads behavioral and psychosocial interventions to focus on what are perceived as the causes of disease, either inherited (i.e., genetic predisposition) or acquired (i.e., lifestyle choices, iatrogenesis). Intervenational research on diabetes in relation to those with severe mental illnesses has largely been conducted from a behavioral perspective, focuses on self-management, is informed by the broader chronic disease management model, and addresses noncompliance. This epidemiologically-informed literature evokes the image of an individual patient who carries clinically distinct biological abnormalities, the correction of these abnormalities is equated with personal wellbeing, appropriate actions are determined by those in expert positions, and patients are expected to closely follow these recommendations in order to achieve wellness. The
individual patient is viewed as having the resources, abilities, and motivation to engage in tasks associated with diabetes management. Instances of self-management failure, therefore, are equated with personal deficiency.

This conceptualization has been challenged in part by the psycho-social perspective, which attempts to combine both individual and social factors, pointing out the importance of environment in personal experiences of diabetes. This perspective in relation to diabetes and diabetes management in general, and in relation to people with severe mental illnesses specifically, acknowledges the variability of patients’ experiences, contrasting it with health care provider perspectives. However, a particular patient continues to be viewed as carrying the same opportunities and possibilities as anyone else, and therefore is expected to successfully fulfill expectations based on provider recommendations. The literature on diabetes and its management within the psycho-social domain continues to explore the importance of social environment from the understanding of determinants, or technical variations in diabetes management to be fixed. Therefore, even though psycho-social approach to diabetes and diabetes management provides an important contribution to diabetes literature and clinical practices by focusing on individual experiences and how they differ across diverse social environments, it remains limited in its ability to go beyond individual towards social, historic, and political.

Social scientists critiqued this focus on individual personal experiences, arguing that this sole emphasis may “blind researchers to the broader social context in which those experiences are played out” (Smith, Mitton & Peacock, 2009, p.1168). Conceptualizing a patient with diabetes and severe mental illnesses as an independent-acting agent, where environment is seen only as a technicality to be overcome neglects the complexity of societal context and how it is organized socially and politically. This is potentially dangerous for those diagnosed with severe mental
illnesses as it “…portrays the society as a composition of undifferentiated, voluntaristic actors engaging in rational, pluralistic politics” (Wood & Wardell, 1983, p.91). This fosters uncritical acceptance of the existing order, while ignoring the constraining character of social structure. Therefore, while the epidemiological and psychosocial conceptualization of diabetes and diabetes management in severe mental illnesses can map the contours of the problem, they do not sufficiently explain patients’ experiences in relation to social context. Consequently, they cannot explain how these experiences are socially developed, which is a strength of critical social science research (McKenna, Richardson & Manroop, 2011).

Social Science Literature on Diabetes Management

Introduction

Alongside medical preoccupation with disease and its clinical (or functional) sequelae, social science researchers have critiqued the understanding of chronic illnesses as merely physiological dysfunction or a consequence of volitional behavior. Instead, they argue that this understanding ignores the deeper social, economic, and environmental determinants of health and illness (Egger & Dixon, 2014). Rather than review the entire canon of social science theory in this area, I have restricted my review to the time period within last fifteen years and focused on qualitative research relevant to my topic.

The social science view has long been used to argue that chronic illness as an experience is developed within a social context that is defined by broader historical, political, and economic influences and therefore cannot be separated from it. In this research, the main argument is that illness experiences go beyond the biological and psycho-social understanding of illness as influenced by environment, but limited to interpersonal and cultural contexts. Qualitative
inquiries allow researchers to specifically research interactions between subjectivity, context, and social structure to understand how these interact in order to develop a particular phenomenon (see for example Parsons (1951) in his Illness and the Role of the Physician: Sociological Perspective; and Michael Bury (1991) with The Sociology of Chronic Illness: a Review of Research and Prospects. However, despite scholarly advances in the field of qualitative research exploring illness experiences (see Bury, 1982, 2001; Corbin, 2002; Charmaz, 2000; Hubbard, Kidd & Kearney, 2010; Larsen, 2009 as cited in Chapter 2, Larsen & Lubkin, 2009; Williams, 2000), studying diabetes experiences in relation to specific societal organization remains challenging. Understanding diabetes within its context has not been much studied (Pierret, 2003), and may well be difficult for the discipline of public health where individual-focused and behavior-driven conceptualizations prevail, and a focus on multiple overlapping complexities is avoided.

Social science scholars argued for a shift in research focus from the understanding of illness experiences through biological and physiological lenses towards the understanding of illness experiences as social and political. Social science writings of illness experiences provided knowledge about the circumstances under which certain populations lived, focused on patients as pivotal players in health care, and emphasized how people come to view themselves as chronically ill and how it affected their lives (Charmaz, 2000). Research built on the underlying premises of critical social science, specifically on understandings informed by social constructionism, might be a better approach to uncover these aspects in patients’ experiences of illnesses (Scotland, 2012).
The Social Construction of Illness Experience

In medicine, as I have demonstrated, chronic illnesses are viewed as physiological/biological in nature, measurable, and homogenous, meaning they are the same across populations and cultures. Social science literature provides an important counterpoint to this medical deterministic approach to disease and illness by emphasizing experiences in relation to their development from and within a particular social context, understood as the result of intersections between the social, historical, and political (Conrad & Barker, 2010). This marks a departure from analyzing a phenomenon as a self-contained entity with distinct measurable and discoverable characters towards an understanding of a phenomenon as shaped and framed by social context. In their critiques, many social scientists argued that understanding complex phenomenon as separate from context is insufficient, because this neglects external structural forces that influence individual behaviors. They have called for research inquiries that examine phenomena as “structured historically in the traditions, prejudices and institutional practices that come down to us” (Taylor, 1993, p.59).

Illness Experience through the Lens of Critical Perspective

Social science research in health and illness accepts that knowledge is not neutral and cannot be separated from wider societal interests (Prasad, 2005); and therefore, all fields of knowledge creation (e.g., health, psychology, economics) are mediated by power relations that are socially and historically constituted (Kincheloe & McLaren, 1994). This aligns with what is called critical perspective. From this perspective, research participants and researchers are both seen as subjects in the dialectical tasks of unveiling reality, critically examining it, and recreating that knowledge (McCoy, 2007; Scotland, 2012). In particular, I have been interested in reading studies that employed the critical theoretical perspective (Dale, 2013; Deveau, 2011; Lowndes,
For critical scholars, illnesses are not considered homogenous and illness experiences are not formed in a vacuum, and therefore the focus is on how peoples’ every day experiences are organized within social institutions, which are in turn socially and politically constituted.

To demonstrate, Bourgois et al. (1997) study highlighted how the organization of health practices can shape the lives of those diagnosed. The authors conducted an ethnographic study on the homeless population in San Francisco that explored the risky behaviors of needle sharing. They demonstrated how well intentioned self-help messages of harm reduction further alienated street addicts as these messages resonated only with middle class users. The authors argued that a “moralistic medical establishment” (p. 161) promoted unrealistic slogans laden with symbolic violence, and demoted street addicts and those with HIV to the category of self-destructive other.

This idea that social arrangements, whereby human beings in a society interact and live together, (re)produce conditions (Smith, 2005) that may potentially result in practice deficiencies and jeopardize the wellbeing of those it intended to help, was also echoed in DeForge et al. (2011) study of long-term care homes. In this work, the authors demonstrated that policy-driven mechanisms, specifically the use of standardized resident assessment instruments, resulted in a culture of blame towards frontline staff by replacing caregiving responsibilities with caregiving accountabilities. The policy-driven accountability framework shaped practices of caregiving/receiving in such a way as to leave health care providers afraid and unable to care.

Similar ideas are reported by Kontos and colleagues (2007, 2010, 2011) across several studies in long-term care facilities. Using ethnographic inquiry, the authors demonstrated how the compliance of personal support workers with regulatory policies during care delivery
constrained their abilities to engage in individualized care, forcing them into practices of rule breaking (Kontos et al., 2010). They argued that understanding the relationship between context and its impact on personal experiences enables an understanding of complexity and ‘messiness’ as it occurs in real life, which is crucial if one is to successfully embed interventions in settings, thereby ensuring greater impact and sustainability (Kontos & Poland, 2009).

Social science literature on illness experiences as a social construction provides a useful conceptualization of illness not only as biologically and physiologically shaped, but also as strongly influenced by social location. This social context is recognized as developing within a particular historical and political reality, not simply present in nature to be discovered. This shift in understanding allowed for researchers in the field of mental illness to reconceptualize patients’ decision-making behaviors through the concept of stigma. The corpus of literature on stigma in severe mental illnesses is large. In relation to noncompliance, it has been found that internalized stigma, or the way stigmatizing messages are taken in by an individual and applied to the self, are positively associated with the severity of psychiatric symptoms, and negatively associated with treatment adherence (Livingston & Boyd, 2010). In people with severe mental illnesses, stigma has been linked to low rates of help-seeking and poorer quality of physical healthcare (Thornicroft, Rose & Kassam, 2007). To complicate matters, obese individuals without severe mental illnesses population are also highly externally stigmatized, and face multiple forms of prejudice and discrimination because of their weight (Sobal, Brownell, Puhl, Schwartz & Rudd, 2005; Schabert, Browne, Kylie & Speight, 2013). A systematic review on stigma and obesity demonstrated that weight bias translates into inequalities in care, often due to widespread negative stereotypes that those diagnosed are lazy, unmotivated, lacking in self-discipline, less competent, sloppy, and overall noncompliant (Puhl & Heuer, 2009).
Research on stigma focuses on how wider social factors constrain personal ability to choose whether to comply or not with medical recommendations. These researchers advocate for a shift away from labeling noncompliant patients as lacking in self-discipline, motivation, and competence, and instead to question the understanding of noncompliance as an individual trait and a simple behavioral act. Therefore, new research has called into question the understanding of diabetes management as solely located within pathology and behavior, moving towards a psychosocial understanding, where individual health behavior is viewed as influenced by one’s social, economic, cultural, and physical environment (Sabourin & Pursley, 2013; Young & Unachukwu, 2012).

**Structural Processes as Revealed through Individual Practices**

Dorothy Smith’s (1987) efforts to explicitly address “a silence, an absence, or nonpresence” (p.20) of participants’ experiences in research resonates specifically with the objective of this project. Smith directed research focus towards the wide range of practices people engage in around their experiences. Her argument is that in order to understand how one phenomenon works we need to switch our focus to analyzing a range of diverse practices performed by an individual within their reality of daily living, as it will allow us to understand their relationships to a broader context (Smith, 1987, 2005).

Smith’s (1987, 2005) practice-based research approach has been successfully used by a number of scholars working in the field of chronic illnesses who have demonstrated how broader social organization may exacerbate the physical limitations imposed on the individual by disease. For example, in the 2008 study by Deveau on workplace accommodations for people with physical disabilities, the author demonstrated how regulatory practices result in alienation and exclusion, rather than increased access for those with physical limitations. Moll (2012) explored the
notion of equity for employees with mental illnesses when seeking accommodations at the workplace demonstrating how the way major institution operates impact employees’ disclosure of mental illness, and ramifications it may have for both practices and individual wellbeing.

Several representative studies within this field of research have used the term of ‘work,’ which broadly referred to any actions performed around treatment regimes, to put into view a range of hidden activities in which participants engaged and their social and historic factors. For example, Markoulakis’s (2014) doctoral work examined the notion of accessibility for university students with mental health problems. She demonstrated how accessibility was regulated within the university bureaucratic apparatus, which switched the focus from accessibility to accommodation. She further explored how work was created for individual students seeking access, and how these relationships operated under assumptions of mental wellness, which presented challenges for students with mental health problems. In similar fashion, Mykhalovskiy and McCoy (2002) explored the health work engaged in by those with HIV. The authors connected treatment decision-making to a wider array of social relations, which generated new and sometimes contradictory health work for patients.

These studies have demonstrated how personal experiences are organized from and within social context, and how this new understanding is able to bring new insights to a variety of health phenomena including the health work of patients.

Diabetes Management Experience through the Critical Perspective

Scholars argue that traditionally oriented diabetes management research with a focus on clinical issues problematizes only the patient’s viewpoint, while treating the provider’s perspective as an incontrovertible point of departure. This bias is inherently problematic for developing patient-
centered practices as patients’ voices are rarely heard, and have limited opportunity to influence policies or practices. The social constructionist perspective, with its focus on experience as reflecting a broader context, places the experiences of those living a phenomenon at the center of the research inquiry.

For example, Hunt and Arara (2001), and Hunt and colleagues (1998, 2013) used the lens of social constructionism to conduct research with diabetic patients and their medical providers. They explored how broader institutional and economic contexts of illness management impacted patient and provider perspectives. The authors critiqued the concept of noncompliance in people with diabetes as too simplistic for complex and long-term regimens. They identified that providers misconstrued patient experience as the result of lack of knowledge or intention to perform the target behaviors, and providers mistakenly exclusively focused efforts on educating and motivating patients to change. The use of theory-informed research inquiry allowed the authors to focus on the patient perspective, which did not support the provider view that patient behavior was a result of error or deficiency. Hindhede (2014) echoed this understanding in her Bourdieusian critique of prediabetes categorization. She demonstrated the gap between medical understanding of prediabetes and patients’ experiences of being positioned as a new “high risk person” who was expected to take action. The author argued that the social consequences of diagnostic labels are not accessible through traditional means of quantitative inquiry. Consequently, approaches which combine micro and macro views should be employed if we are to understand a complex phenomenon from the position of a sufferer.

Loewe and colleagues (1998) analyzed narratives of providers and of patients with diabetes to identify how individuals construct meaningful explanations of disease by drawing on cultural and personal resources. In approaching diabetes narratives with a sociological lens, the authors argued that diabetes narratives, especially those emphasizing control, are part of a larger social
discourse in which disease (similar to poverty and homelessness) is considered the result of an individual’s failure to achieve autonomy. Similarly, Lawton et al. (2005), and Lawton and colleagues (2008) in their longitudinal qualitative study involving 20 patients with type two diabetes followed and interviewed over a 4-year period, demonstrated that experiential knowledge of chronic illness was essential to understanding continuities and changes in health practices. The authors concluded that social cognition theories prevalent in diabetes and diabetes management research are limited as they lack in recognition that “disease accounts do more than convey beliefs and understandings about aetiology” (Lawton et al., 2008, p.54). They also pointed out the importance of analyzing social context, and ways it is implicated in everyday health management.

This group of studies demonstrated that theoretically informed research, specifically those using the lens of social constructionism, is valuable in providing an understanding of diabetes as contextually driven, and developed within particular social and historic milieus. This theoretical orientation yielded important insights into how the experience of diabetes is embedded in a wider set of social relations, knowledge not accessible through traditional quantitative inquiries. In line with this understanding, critical methodology is directed at interrogating values and assumptions, challenging conventional social structures, and engaging in social actions through a variety of methodological inquiries.

**Ethnographic Accounts**

An ample amount of sociological research written from the ethnographic perspective has examined interactions between social context and illness experiences, bringing attention to the role of dominant knowledge and ideology in constructing these experiences (Baumbusch, 2011). This literature aims to generate empirical data wherein the cultural, historical, and political
contexts of illnesses are fully acknowledged. Therefore, research is conducted with the understanding that reality is socially constructed and contextually constituted, which creates an opportunity for change or reform to enhance the lives of participants.

To demonstrate, Gomersall and colleagues (2011) conducted a meta-synthesis of ethnographic research on type II diabetes self-management. They demonstrated how the idea of self-management is not developed on its own as a neutral entity, but is instead produced through a biomedical perspective. This raised questions about dominant discourses in diabetes care, such as the discourse of personal responsibility, and ways this discourse reflects the broader ideology of individualism, as well as the implications this might have on patients when improvements in the condition are believed to be predicated on the capacity for self-determination.

Ethnography has been especially useful in uncovering the interplay between personal illness experiences and the broader social, institutional and political contexts across countries and different ethnic groups; knowledge which is not accessible or visible through tools of epidemiological research. For example, the work of Clark and colleagues (2009) with Mexican Americans with diabetes demonstrated that views of diabetes management and diabetes were a result of the employment, income, and housing situations of individuals and families, and therefore these views were characterized by the political and economic settings in which participants lived. Similarly, Guell’s (2011) study on Turkish migrants with diabetes in Germany explored diabetes as a social experience, where social practices and experiences were intrinsically linked to social, cultural, political, economic and moral factors, and were not merely a result of individual behavior. In their research, the authors demonstrated that the use of ethnographic inquiry enables researchers to depart from conceptualizations of health that focus on the individual and individual behavior towards an understanding of how personal experiences are intrinsically linked to individuals’ social worlds.
Therefore, critical ethnographic research has provided important insights into the workings of various places and spaces in health care (Baumbusch, 2011). Research in chronic illnesses explored through critical ethnography extends our understanding of chronic illness as being intrinsically linked to social institutions, and emphasizes that experiences of illness are thus largely socially constructed (Guell, 2011). All diseases have a biological basis in the sense that all human function and dysfunction are manifested in the body. However, our perceptions of the underlying processes are shaped by social, political, and economic beliefs, values, ideologies, assumptions, and practices (Kleinman, 1988). This broader understanding of illness as socially constituted is missing in traditional examinations of diabetes and its management in people with severe mental illnesses, where research continues to focus on its biological, physiological, and behavioral aspects.

One key study, specifically doctoral work by Ruth Lowndes (2012), adopted a critical perspective in exploring diabetes care in people with mental illnesses. Given the close relationship between my work and Lowndes’s, I mention her work here in particular detail. In her study, Lowndes analyzed the personal illness experiences of diabetes in women diagnosed with severe mental illnesses and living in a rural residential care facility. She focused analytically on the everyday practices of residents as they struggled to manage their diabetes in this setting. She carefully explicated how residential care facility regulations, and resource rationing as a consequence of these regulations, affected the extent to which residents could adhere to physician prescribed diabetes self-management regimes. Lowndes identified that policies that were supposed to be helpful instead constrained the abilities of patients to manage their care. Lowndes combined qualitative methods of interviewing and observations with text analysis.
Similar to Lowndes, my study is also directed at understanding practices of diabetes in severe mental illnesses by exploring how the social organization of diabetes self-management impacts individual lives. I have however used a different methodological approach focusing on insider’s perspectives to explore the experience of both men and women who live in the community, and receive health care from a primary care setting located at an urban setting, where patients are expected to be more autonomous than are residents in a group home.

Chapter Summary

This chapter reviewed three distinct literatures relevant to the topic of diabetes and diabetes management in the context of severe mental illnesses.

The first body of literature I reviewed locates diabetes and mental illness within biological, physiological, and behavioral domains. This biomedical perspective focuses on diabetes management through its psychological and environmental characteristics. The second body of literature introduced psycho-social studies, which examines individual behavior and from which the concept of patient self-management emerged in the 1990s. While an improvement over biomedical studies, the model of self-management focuses on the concept of patient behavior as a series of logical choices and largely ignores the larger social and political contexts in which patients’ lives are embedded. The third body of literature, the social science literature on illness experiences in general and on diabetes in particular, includes qualitative and institutional ethnography studies. From this work, I have come to understand how both biomedically and psycho-socially defined understandings of diabetes do not fully capture the complexities of an individual’s experiences.
Recent shifts in understanding complex health phenomenon point towards a need for methodological approaches that are more critical. While the examinations of biological and behavioral aspects remain important, they obscure the social and human aspects of living with disease. This gives rise to the importance of studies that focus on the exploration of how social contexts shape and impact personal experiences around diabetes (Kuile, Rousseau, Munoz, Nadeau & Ouimet, 2007; McKenzie et al., 2010).

There is a need for research employing a social science critical epistemology to uncover the complexity of diabetes management in people with severe mental illnesses. To date, there has been no work addressing the experiences of diabetic women and men with serious mental illness living in urban assisted housing. This work aims to address this gap. The next chapter will detail this research project’s design, theoretical orientation, ethical considerations, data collection and data analysis strategies, as well as quality and rigor.
Chapter 4: Research Design

The purpose of this work was to understand the problem of diabetes management in people with severe mental illnesses through patients’ narratives, whose voices remain underrepresented in clinical practices and public health policies. In particular, I was interested in understanding the phenomenon of diabetes management as organized by social, historic, and political contexts in relation to how these arrangements inform patients’ realities and shape diabetes management practices. The aim of this project was to illuminate the inequalities that exist in diabetes practices for this population with the aim to transform clinical care which is largely biomedical in nature, and therefore does not take into account the realities of most patients’ lives. Epidemiological approaches, with their focus on objective unquestionable reality, are limited in their ability to answer these objectives. Therefore, I will next explore the theoretical framework I identified to answer the objectives of this study, followed by a discussion of how this theoretical framework further informed my data collection and data analysis.

Theoretical Framework

As I have identified through my literature review epidemiological and physiological discourses, with their focus on physiological processes and lifestyle behaviors, dominate the field of diabetes care. These discourses continue to define how health services are designed and delivered, thereby driving interventions towards such strategies as lowering body weight through diet and/or exercise. In line with this, public health research also continues to focus on illness management with an understanding that particular behavior change remains an individual responsibility. Individuals are presumed to have complete control over their health and, in essence, choose whether to be healthy or not (Cook, 2005). In keeping with this perspective,
diabetes care continues to be understood as a technical challenge, with little attention paid to the politics and social relations which shape it. The limitations to this approach have been pointed out by social science scholars, who call for a new perspective whereby a public health focus is introduced to counter this victim-blaming ideology, a goal which can be achieved by situating health phenomena as socio-economic-political creations (McCabe & Holmes, 2014). In order to do that, a different theoretical and methodological approach to inquiry is needed, one which privileges the view of the insider, and builds on acceptance of multiple realities and interpretations of a phenomenon, which is contextually, historically, and politically constituted (Cruickshank, 2012; Embree, 2009).

The topic of interest in this thesis was to understand the lived realities of those suffering from both diabetes and mental illness. Therefore, ethnographic inquiry was a good fit as it privileges the worldview of the insider, encouraging the researcher to observe and learn from participants about their everyday lives (Breda, 2013). Ethnography has its earliest roots in social anthropology, which traditionally focused on small scale communities that were thought to share culturally specific beliefs and practices (Savage, 2000). Ethnographic inquiries, with their focus on observations over a substantial period of time to facilitate in-depth understanding of a particular phenomenon, has gained increased popularity in research interested in analyzing the social and cultural dimensions of ill health and health care (Lambert & McKeivitt, 2002). A core conceptual feature of anthropology, specifically its understanding of a phenomenon as socially and culturally specific, is particularly useful for this work. Anthropology’s focus on documenting complex details of everyday lives “provides an important corrective to misleading generalizations and abstractions that can […] grotesquely flatten the diversity of different settings” (Lambert & McKeivitt, 2002, p. 211). This understanding is also important in the field of public health, where a focus is on understanding of complexity and human behaviors, aspects
best understood through observing, and documenting, knowledge not accessible otherwise through epidemiological inquiries. This attention to personal experiences and contextual realities allows the researcher to enter this insider standpoint with an agenda to construct new emancipatory practices (Jordan & Yeomans, 1995).

In line with this emancipatory mandate of other critical ethnographers, my research builds upon critical theory as a philosophical underpinning and a theoretical lens which further informed my data collection and data analysis. Critical theory is an umbrella term used to describe a way of thinking that focuses on critique of power structures in society and culture, and includes numerous sub-schools of thoughts (Breda, 2013). Various theoretical developments emerged under this umbrella: starting from its German origins with such prominent thinkers as Kant, Hegel, and Marx who viewed socio-economic relationships and capitalism as the basis of oppression in society; to Foucault with his focus on discourses and relationships between power and knowledge (Denzin & Lincoln, 2011; Ross et al., 2016). Despite some profound differences among these various schools of thoughts, all critically-oriented approaches are fundamentally similar in that they recognize that the unequal distribution of resources in society leads to the oppression of some groups by others, either overtly or covertly. Critically-informed schools seek to create a fundamental social change through exposing these systemic inequities (Denzin & Linkoln, 2011; Gullion, 2015; LeCompte & Schensul, 1999; Smyth & Holmes, 2005).

The commitment of my work is to illuminate the inequities and contradictions with the aim to change them. This aim requires the use of an analytical approach which allows challenging views that privilege the interests of dominant groups in society, and maintains the point of the insider, namely critical ethnographic inquiry (CE). CE is most appropriate for this work as I sought to examine biomedical discourses, surely one of the most dominant and privileged in our Western society, through the lens of those who are marginalized, such as those living with
mental illnesses, arguably among those most stigmatized and lacking in representation. The combination of both ethnographic inquiry and critical lenses allowed me to focus on both individual realities and the political and social aspects of diabetes care delivery.

**Critical Ethnography as a Research Inquiry**

Critical ethnography (CE) is a research approach that is particularly useful in addressing the abovementioned study objectives, as this is a methodology which not only adopts the insider view, but also focuses on the relations among knowledge, society, and political action (Breda, 2013).

In addition to this, conceptually I also draw on Foucault’s ideas around the ways discourses define how people can think about certain things and not other things – for example, the discourse of self-management does not allow us to consider those aspects of care that might fall outside of a person’s agency. Methodologically, I also incorporated Dorothy Smith’s notion of work, where work is defined as anything that people do that takes time, effort, and intent (Smith, 2005). This allowed me not only to understand work performed by people living with diabetes and mental illness, which is largely hidden and unrecognized, but also to see participants as subjects rather than objects of research.

Therefore, this research is nested within a broader paradigm of critical social science with its epistemological understanding of knowledge as both socially constructed and influenced by power relations (Scotland, 2012, p. 13). CE is also a particularly good fit with marginalized populations as it “aims to change [the order] by analyzing hidden agendas, taken for granted assumptions, and working towards disrupting the status quo by bringing into light systems of power and control” (Baumbusch, 2011, p.185).
My research focuses on what patients diagnosed with several mental illnesses actually do on a daily basis to manage their diabetes. The aim is to understand diabetes management in people with severe mental illnesses through their lived experiences, and analyze how diabetes management - as organized and promoted by clinicians through a biomedical perspective - shapes the lives and daily activities of those diagnosed. The primary objective of this study is to critically examine the process of diabetic management as it is taken up by people diagnosed with severe mental illnesses, using a primary care health setting where diabetes management practices are delivered to people with severe mental illnesses as a point of access.

Critical ethnography informed my data collection and analysis in that:

(1) First, it directed me where to begin, specifically in realities of participants living with mental illnesses and diabetes

(2) Second, it pointed toward what to look for. Specifically, I looked into dominant practices, contradictions, and invested interests to determine what social discourses are prevalent and the ways these discourse inform patients’ realities

(3) Last, it impelled me to use reflexivity as a process to examine my own social position of privilege, and the ways it impacted both this research project and my personal understanding of clinical practices. This whole process was reflexive and pushed me to think about clinical practices and possibilities in a different way.

The findings of this work are consistent with the overall agenda of critical ethnographic inquiry by highlighting social injustices in diabetes care in people with severe mental illnesses and attempting to give power back to those who lack it.
The Conversational Map: an Instrument and a Discourse

I chose to organize my findings around the Conversational Map which is a *clinical managerial framework* and an *instrument* used by clinicians in routine practices when working with patients. I was introduced to this tool during my first on site visit, when clinicians described the delivery of diabetes care to this population. Clinicians participated in specialized training, organized by a pharmaceutical company, Eli Lilly, a leading player in diabetes medication production and a developer of this educational tool.

Conceptually, the Conversational Map is built upon clinical guidelines which are informed by evidence-based practices. Therefore, the Conversational Map offers us a visual capture of a discourse which orients diabetes care around compliance to self-management with medications and lifestyle behaviors, where maintaining one’s physical and emotional health is assumed to be a personal responsibility. Each step on the map can be interpreted as a representation of evidence based medicine, which is built on knowledge produced through epidemiology, and therefore numbers and statistics (Breda, 2013; Scotland, 2012). It does not include patients’ experiences. Rarely is evidence-based philosophy so well mapped out for us as it is through this pharmaceutically produced Conversational map.

Therefore, my use of this Conversational Map was threefold. First, by mapping patients’ experiences onto the Map, I was able to compare and contrast the differences and gaps between biomedically produced knowledge and patients’ knowledge. This strategy allowed me to identify where and when the realities of marginalized groups did not align with presumed best practices in diabetes care. Secondly, it was practical, as patients were very familiar with the clinical regime and therefore using this map kept me grounded in patients’ realities all through
this project. Lastly, it was emancipatory, as it offered study participants a way to speak back to
the biomedical model being imposed on them.

Ethics

Ethics in research can be understood both as procedural and values-based. In terms of the
procedural aspects of obtaining ethical approval for this study, I followed the Tri-Council Policy
Statement on Ethical Conduct for Research Involving Humans. I ensured my protocol was in
compliance with the approval and ethics standards processes of the University of Toronto
Research Ethics Board.

In terms of values, diabetic patients with mental illness are a vulnerable group. Consequently, it
is important to ensure that research with them is not exploitative, stigmatizing, or
disempowering. In my “Participants Interviews” section, I provide a more detailed discussion on
the particularities of the historical mistreatment of this population in research, the major
misconceptions regarding the knowledge they bring into the research process, and the strategies
I used to address their vulnerabilities.

Underpinning this study is my personal commitment to the standpoint offered by Madison
(2005), who defined ethical responsibility as a “compelling sense of duty and commitment
based on moral principles of human freedom and well-being,” with the goal “to address
processes of unfairness or injustice within a particular lived domain” (p.5). In order to at least
partially achieve this, I ensured that consent was obtained continuously rather than at a single
point, during on-site observations and interviews. Through my data collection and subsequent
analysis, I have also tried to remain true to representing the information patients so generously
shared with me. Some studies employ a participant-action approach to ensure that participants
have a voice in analysis and dissemination. I did not undertake this step. However, I did share
my results in consequent interviews with respondents, testing and reshaping my questions as they come along. I also remained mindful about power differentials between myself and participants by keeping detailed reflective memos, and encouraging participants to share any feelings or discomfort that arose as a consequence of interviews. Lastly, I attempted to address requests for help, when these occurred, by providing respondents with information or directing them to the appropriate source.

**Ethical Guidelines**

Ethical guideline requirements were met and approved by the University of Toronto Research Ethics Board through a formal process. I obtained ethics approval for interview guides for participants diagnosed with severe mental illnesses and diabetes (see Appendix II: Interview Guide I: Entry-Level Informants); and for health professionals and administrators (See Appendix III: Interview Guide II: Health Professionals and Administrators). I also obtained ethics approval for recruitment materials, such as the Recruitment Flyer (see Appendix IV: Recruitment Flyer: People diagnosed with Severe Mental Illnesses & Diabetes, and Appendix V: Recruitment Flyer: Health Professionals & Administrators); and an Informational Sheet to provide brief description of my project to participants (see Appendix VI: Informational Sheet). Ethics approval was also granted for additional materials associated with recruitment, such as explanation on the screening (see Appendix VII: Screen Sheet), and observations (see Appendix VIII: Observation Guide. Field Work). Additional ethics approval was obtained for the informed consent forms that were used prior to interviewing participants diagnosed with severe mental illnesses and diabetes (see Appendix IX: Informed Consent Form for People Diagnosed with Severe Mental Illnesses & Diabetes) and health professionals and administrators (see Appendix X: Informed Consent Form Health Professionals).
Participants with severe mental illnesses and diabetes who expressed their interest in participating in this research study and approached me directly or through their medical providers, were provided with the Informational Sheet (see Appendix VI: Informational Sheet), and were given as much time as they needed to consider their involvement. I also explained this study to participants and their questions were answered before obtaining signed consent. Participants were advised that they could withdraw from the study at any time. As this project included on-site observations of patients’ groups and clinical meetings, informal verbal consent from those not directly participating in this study were also obtained throughout the project. At each clinical meeting and when observing clinical practices, I introduced myself, briefly stated the purpose of the research study, and sought participants’ permission to observe and take notes.

**Ethical Principles**

This research investigation closely adhered to ethical principles defined by the Tri-Council policy statement on ethical conduct for research involving humans, specifically respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). These ethical considerations were particularly applicable to the research design of this project. In terms of the principle of justice, one of the objectives of this study was to increase awareness of the ways in which the organization of clinical practices could influence the personal wellbeing of patients. It therefore entailed an ethical commitment to safeguard the information shared by participants in interviews and field observations, which was achieved by excluding all potentially identifiable information, including the names of participants, specific places, and medical centers with which they may have been affiliated.
Concern for welfare implies consideration for personal experiences of life in all its aspects, and this was protected through careful deliberation of potential foreseeable risks associated with respondents’ participation in this research. This included stigmatization and discrimination, or damage of reputation in relation to the primary health care setting (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). The same principles were used to ensure anonymity and confidentiality of all information collected during this study.

The principle of respect for persons recognizes the intrinsic value of human beings, and incorporates a dual obligation to respect personal autonomy while also protecting those with developing, impaired, or diminished capacity (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). In this regard, it was important for me to recognize and acknowledge my own social location as a clinician who may be viewed by patients as being in a position of power, which might negatively influence or compromise respondents’ exercise of autonomy. To meet this ethical principle, I adopted an approach of a “novice person” when I asked participants to teach me what and how they perform their diabetes management, and I left it open to them to decide on the depth and breadth of information to share. The consent form included a section where potential participants were asked to explain their understandings of the project, what was involved, and associated risks and benefits. This afforded me the opportunity to discuss and clarify any aspects that appeared to be unclear to potential participants, and also to ensure that respondents had a full understanding of informed consent and the choice of whether or not to participate in this research project.
The Research Site: Family Health Team (FHT)

Family Health Teams are primary care organizations, which include an interdisciplinary team of medical professionals, including family physicians, nurses, and allied professionals (e.g., social workers, nurse practitioners, dietitians, and others); along with management and administrative personnel providing support to health providers. In response to Canada’s growing health care burden of chronic conditions, a number of primary care reform models have been developed across the country over the past decade (Rosser, Colwill, Kasperski & Wilson, 2011). Research shows significant disparities in health and accessibility for different populations, such as ethnic minorities, people with disabilities, and immigrants in Canada (Carter-Pokras, Offutt-Powell, Kaufman, Giles & Mays, 2012; Frohlich, Ross & Richmond, 2006; Townsend, Langille & Ripley, 2003). The FHT was introduced as a model to allow greater focus on chronic disease management. Ontario’s FHT strategy was developed in 2005, building on a concept of the principles of the patient-centered medical home endorsed by the American Academy of Family Physicians and the American College of Physicians (Rosser et al., 2011). The principles focused on seven areas: the availability of physicians; physician-led practices with salary and bonus based remuneration; whole person approach aimed at enhancing access; coordination of care; quality and safety; and effective patient-centered primary care services (Dolovich, 2012). The FHT model marks a departure from the traditional model of uniprofessional practice and encompasses goals, which include the provision of patient-centered care, improved access to a variety of health professionals, and increased emphasis on chronic disease management, health promotion, and disease prevention (Forster et al., 1994; Meuser, Bean, Goldman & Reeves, 2006). FHT’s innovative funding system through blended capitation (combination of per capita, fee-for-service payments, and bonuses) aims to enable physicians to participate in consultative and collaborative activities that are not reimbursed under the previous traditional fee-for-service
payment (Mulvale, Danner & Pasic 2008). The FHT model focuses on chronic care
management, disease prevention and health promotion, which are customized to respective
community needs (Howard, Brazil, Akhtar-Danesh & Agarwal, 2011; MOHLTC, 2005, 2012;
Russell, Dabrouge, Geneau, Muldoon & Tuna, 2009). Its flexibility and 7-day-a-week access (in
person or/and over the phone) for patients makes it a compelling primary care model for
populations with complex needs and comorbid conditions.

Negotiating Access

Ethnographic studies typically begin with a gatekeeper who helps the researcher initiate contact
with potential informants (Schensul, Schensul & LeCompte, 1999), be accepted by the research
population (Hammersley & Atkinson, 1983), and gain access to information (LeCompte &
Schensul, 1999).

Despite initial indications to the contrary, organizational access to the primary care setting for
this study proved to be problematic. Originally, I intended to access FHTs as a part of a bigger
randomized controlled trial for people with diabetes and mental illness conducted in several
primary care settings across the greater Toronto area by my then-PhD supervisor, who is a
licensed psychiatrist and a principle investigator for that project. The initial intention was to
research a fairly large and well-established primary care setting located north of Toronto, which
serves a large population of people with numerous medical and psychiatric conditions.
However, as the nature of my research work required the utilization of in-depth interviews, and
my close on-site attendance with involvement in a fair number of the FHT’s daily operations,
my access was refused on the grounds that the primary care practices were too busy to
accommodate my presence. I realized that quantitative, structured and time-limited research
studies were the most preferable options for health and administrative practitioners, given their
perception of time constrains and limited resources. After much consideration and significant assistance from the supervisor, I approached another primary care team that, although smaller in size and newer, had closer ties with one of the major psychiatric hospitals in the city and served a large population of those diagnosed with severe mental illnesses. Access to the setting was facilitated by my supervisor through email introduction to the FHT senior administrator, where I was introduced as a clinician and an internationally trained psychiatrist working on her PhD at a major university who was interested in exploring diabetes care in persons with severe mental illnesses. I believe the positioning of myself as somebody who is skilled in medical practices was an important factor in facilitating access to this research site. Before access was granted, I delivered several presentations to the clinical team explaining the purpose and logistics of my research study. While well received, my presentations led to staff members enquiring about my methods, sampling strategy, and the generalizability of results, which are quantitative metrics for assessing research rigor (see for example, Feldstein & Glasgow (2008) discussion on PRISM framework, or the CONSORT (n.d.) guidelines). These exchanges shed light onto what type of research inquiries may be more familiar and expected in medical settings, and the difficulties associated with using other paradigms with this audience. Clinical experimental research study designs that quantified, explored cause-effects, and assessed the effectiveness of outcomes seemed to be more familiar and readily accepted.

Setting Description

The choice of FHT for this research undertaking was pragmatically driven. The research site was located in the central part of Toronto, Ontario. The setting’s physical space was built to address the specific needs of a FHT, in that both family practitioners and allied clinical staff shared the same space. This physical layout provided the unique opportunity for continuous on-
site communication between clinicians, as confirmed by team members on numerous occasions and observed during my fieldwork. The layout is unlike other FHTs where physicians and allied health staff may be spatially, even geographically separated. This FHT was located on the first floor, which it shared with a pharmacy, of a newly renovated and wheelchair accessible building. The FHT featured a big bright hallway/waiting area overlooking the street with both stair and wheelchair access. Several comfortable chairs were placed near the wall facing the reception area, and included a small “child corner” with games and toys. The receptionist area separated the waiting area from the clinical rooms by glass doors, and was equipped with big screen computers on which patients could electronically check-in by entering their names. Receptionists were also available for face-to-face contact. The space also housed a large meeting room with glass windows and a door, located across from the entrance, where team and patients’ group meetings were held.

The FHT operated 6 days a week, from 9 a.m. to 8 p.m., except on Fridays when the clinic closed at 5pm. The clinic was also open on Saturdays from 9 a.m. to 12 noon for urgent access. Telemedicine services were available for afterhours consultations. The FHT housed nine family physicians, one nurse practitioner, two registered nurses, one social worker, one registered dietitian, one chiropodist, one executive director, and an administrative team. A psychiatrist was available half a day weekly, as well as a physiotherapist and a chiropractor. The FHT, in addition to regular medical services offered by general practitioners, also offered a variety of programs. Among those were weekly ‘Metabolic Clinics,’ a group developed for people diagnosed with severe mental illnesses and diabetes, a ‘Flu Clinic’ for vaccinations, a ‘Prenatal Care Clinic’ for pregnant women, and a ‘Well Baby Clinic’ for parents with newborns. There were also several other chronic illness management and prevention programs offered on an as needed basis. The FHT served a diverse population of over 10,000 people, a number that was on
the rise as the FHT grew. About 12% of the FHT patient population had a diagnosis of severe mental illnesses, and of those, from those 175 individuals had been formally diagnosed with comorbid diabetes (personal communication with FHT senior manager, November 2013).

Research Participants

Recruitment

Participants were selected for my study using convenience and snowball sampling, both well-known purposive strategies in qualitative research (Patton, 1990). Convenience sampling in this research project involved interacting with and selecting participants as they moved through the health setting, a strategy used in various other ethnographic studies (Agar, 1980; LeCompte & Schensul, 1999), and upon consultation with my PhD supervisor. Recruitment was conducted in two stages. The first stage focused on recruiting recipients of the FHT’s clinical services who had been diagnosed with severe mental illnesses and diabetes in order to gain understanding of personal experiences with diabetes management. Then, in order to build on the knowledge acquired through patient-oriented interviews and ethnographic accounts, I approached health providers and administrators who were directly or indirectly involved with patients. The intent was to further explore how the personal experiences of patients were aligned with clinical and administrative understandings around diabetes management.

Patient recruitment was conducted through several techniques. First, I promoted my research through study presentations to the FHT’s health professionals and administrators during team meetings (Appendix V: Recruitment Flyer: Health Professionals & Administrators) to facilitate referrals. Secondly, I posted notices of the research project on the FHT’s bulletin boards and online daily broadcast (Appendix IV: Recruitment Flyer: People diagnosed with Severe Mental
Illnesses & Diabetes). Finally, I utilized the snowball technique, which is common in qualitative research, and refers to a strategy whereby study participants are asked to identify potential future participants from among their acquaintances (Sadler, Lee, Lim & Fullerton, 2010). The recruitment of health providers and administrators was similarly facilitated. That is, through personal communication and provision of information, posting notices of the research project on the FHT’s bulletin boards, and utilizing the snowball technique. The majority of health providers were recruited through the snowball technique.

Patients with severe mental illnesses and diabetes who were knowledgeable and/or receptive to this research study were approached by me and offered the opportunity to participate in the study, and if agreeable, were invited to attend an interview at a mutually convenient time and location (see Appendix VII: Screen Sheet). Health providers who could comment on a range of organizational structures and processes that affect care provision to people with diabetes and severe mental illnesses were also identified, approached, and invited to participate in the study. Prior to commencing both patient and provider interviews, oral and written informed consent was obtained from each participant. A copy of the signed and dated consent form was provided to the participants, while I retained the original. Each participant (patients and providers) was provided with a $25 honorarium to cover travel expenses.

**Inclusion and Exclusion Criteria**

Patient participants were required to be adults (18 to 66 years old) with diagnoses of severe mental illnesses and type two diabetes mellitus, which were confirmed through medical charts and in consultations with FHT clinicians. This age range was pragmatically chosen as there are different billing mechanisms in place for adults over the age of 66, and therefore mechanisms of diabetes care provision may differ in scope and particularities.
Severe mental illnesses were defined using the three-dimensional definition by Ruggeri and colleagues (2000). Specifically, individuals who had a medically established diagnosis of any non-organic psychosis (e.g., schizophrenia, bipolar disorder, and major depressive disorder); had a minimum treatment duration of two years, as confirmed by medical records; and scored below 50 as measured by the Global Assessment of Functioning (GAF) scale indicating moderate severity in functioning (Appendix XI: Global Assessment of Functioning Scale) were invited to participate. Eligibility was confirmed with the screening assessment by me, in consultation with my PhD supervisor, before proceeding with the interview. Participants were also required to speak and understand English, be willing to participate in the study, and be competent to provide informed consent.

Provider participants were required to be adults (18 to 66 years old), employed by the FHT (fulltime or part-time) for at least 3 months at the time of the study to ensure their understanding of inner-organizational culture and policies (Moll, 2010), and directly or indirectly involved in diabetes care provision for participants diagnosed with severe mental illnesses and diabetes. They were also required to speak and understand English, willing to participate in the study, and provide informed consent.

Participants

Ethnographic research focuses on explicating and tracing linkages of personal experiences to the broader socio-historical context through in-depth interviews providing a rich amount of data; therefore, large sample sizes are unnecessary (Ritchie & Lewis, 2003). This study included ten participants diagnosed with severe mental illnesses and diabetes, and five health providers, including two registered nurses and one nurse practitioner directly involved in care provision for this population, along with one senior family physician, and one senior administrator.
The average age of the ten participants diagnosed with severe mental illnesses and diabetes was 54.6 years (ranging from 40 to 66 years). Among these, six were women and four were men. All patients were able to communicate in English, although half did not have English as their first language. Half of the participants identified themselves as persons of colour, and half as white. Eight participants identified themselves as being single, one as living in common-law relationship, and one as married. All participants lived in some type of supportive housing. All were of low socio-economic status, and were financially supported either by the Ontario Disability Support Program (ODSP), or by the Canada Pension Plan for Disability (CPP-Disability). Table 1 provides detailed description of the demographic profiles of the patient participants.

Table 1. Participants’ with Severe Mental Illnesses and Diabetes Characteristics

<table>
<thead>
<tr>
<th>Participant Code</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Race</th>
<th>Living Arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>PB01</td>
<td>61</td>
<td>M</td>
<td>SCZ*, diabetes type II</td>
<td>person of colour</td>
<td>Supportive Housing</td>
</tr>
<tr>
<td>OW02</td>
<td>60</td>
<td>M</td>
<td>BP I**, diabetes type II</td>
<td>person of colour</td>
<td>Boarding Home</td>
</tr>
<tr>
<td>CA03</td>
<td>49</td>
<td>F</td>
<td>SCZ, diabetes type II</td>
<td>person of colour</td>
<td>Boarding Home</td>
</tr>
<tr>
<td>PA04</td>
<td>54</td>
<td>M</td>
<td>SCZ, diabetes type II</td>
<td>white</td>
<td>Boarding Home</td>
</tr>
<tr>
<td>MS05</td>
<td>59</td>
<td>F</td>
<td>SCZ, diabetes type II</td>
<td>person of colour</td>
<td>Boarding Home</td>
</tr>
<tr>
<td>AR06</td>
<td>46</td>
<td>F</td>
<td>BP I, diabetes type II</td>
<td>white</td>
<td>Supportive Housing</td>
</tr>
<tr>
<td>JM07</td>
<td>66</td>
<td>F</td>
<td>SCZ, diabetes type II</td>
<td>white</td>
<td>Supportive Housing with higher level of support available</td>
</tr>
</tbody>
</table>
Health providers and administrators included five FHT employees who were directly and indirectly involved in diabetes care management for people with severe mental illnesses. All identified themselves as white Canadians and had an education level of over twelve years. Among these respondents, four were women and one was man. All participants had over three years of clinical experience and training, were employed by the FHT for a duration of over six months, and were involved in care provision for people with severe mental illnesses and diabetes. Table 2 describes the demographic characteristics of participants who were health providers and administrators.

Table 2. Health Providers and Administrators Characteristics

<table>
<thead>
<tr>
<th>Participant Code</th>
<th>Gender</th>
<th>Role</th>
<th>Race</th>
<th>Length of Employment at the FHT (at time of project start)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FM 01</td>
<td>F</td>
<td>Registered Nurse</td>
<td>white</td>
<td>&gt; 6 months</td>
</tr>
<tr>
<td>SL 02</td>
<td>F</td>
<td>Registered Nurse</td>
<td>white</td>
<td>3 years</td>
</tr>
<tr>
<td>DN03</td>
<td>F</td>
<td>Senior Administrator</td>
<td>white</td>
<td>5 years</td>
</tr>
<tr>
<td>KA04</td>
<td>F</td>
<td>Nurse Practitioner</td>
<td>white</td>
<td>&gt; 6 months</td>
</tr>
<tr>
<td>DS 05</td>
<td>M</td>
<td>Physician</td>
<td>white</td>
<td>5 years</td>
</tr>
</tbody>
</table>

*SCZ-Schizophrenia; **BP I-Bipolar Disorder I
Data Sources

Primary data included participants’ interviews, observational field notes, journal entries, and notes from informal interactions. Supplementary or secondary data included organizational documents, patients’ files obtained from the program, electronic medical charts, and regulatory and administrative documents related to diabetes care provision. Not all methods yielded rich information from all participants. Therefore, multiple methods of data collection were important in the development of thick description (Geertz, 1973). This included careful attention to verbatim quotations, which were useful to contextualize other forms of data including files and administrative documents. Interviews and on-site observations were conducted over the period of one year, from September 2013 to September 2014.

Participant Observations

Participant observations are a hallmark of ethnographic research (Spradley, 1980). They may assist in understanding routine setting operations and practices that are difficult to explain in sufficient nuance through interviews alone. A guide to observation (see Appendix VIII: Observational Guide: Field Work) was developed and utilized as a point of reference during my fieldwork. All participants were aware of being observed and had provided verbal consent on each occasion. The focus of participant observations in this study was not limited to diabetic management in persons with severe mental illnesses, but also included health setting operations in general and routine clinical practices. My role as an observer ranged from silent presence (e.g., observing registered nurses during medical exams; attending team clinical meetings involving discussion around patient care), to more active participation (e.g., handling blood collection tubes; helping with breakfast preparation and clean up).
Practice of Observation

Observations were conducted on-site at the FHT during regular hours of operation to capture the range of routine practices. Health professionals and administrators were observed in their natural environment of daily work, with particular attention paid to their organizational practices, rules, and overall work processes to gain an understanding of the major aspects that influence care and define clinical practices. To develop a general understanding of FHT operations and service provision, I had initially negotiated starting with general on-site observations during regular working hours to immerse myself in the setting’s daily practices. However, two weeks following the start of the study, I was directed by the FHT’s senior management to limit my on-site observations. I was advised to focus on activities directly related to the provision of diabetes management, specifically the ‘metabolic clinic.’ This change in access was a result of several complex factors, such as staff stress from ongoing FHT restructuring activities, and concerns that my nonparticipant observations could be possibly disruptive to clinical operations. Consequently, from November 2013 to September 2014, I limited my fieldwork to weekly observations of the metabolic clinic, to clinical meetings related to the care provision of people diagnosed with mental illnesses, and to care directly related to those I interviewed and observed over the duration of this research project.

The metabolic clinic is a program developed by this particular setting to address the specific diabetes management needs of people with mental illnesses. It occurred every week on Thursdays from 8 a.m. to 12 p.m., although it was developed in a way to divide patients with mental illnesses and diabetes in groups, with these groups coming consistently every three months. In this manner, each Thursday a different group of patients was coming, allowing me to observe a wide variety of patients. Each metabolic clinic visit included three components: (1) a
medical component, when all medical indicators and blood collection were taken by the registered nurse; followed by (2) a ‘healthy breakfast,’ when patients were provided with breakfast to prevent a drop in their blood sugar levels as they were asked to fast before coming for their appointment due to the blood work; and concluding with (3) an educational module where psychoeducation and discussion on diabetes management occurred. As the project progressed and medical team became more accustomed to my presence, I also observed several team meetings specific to diabetes care provision in persons with severe mental illnesses. Specifically, I observed the regular team meetings held on Tuesdays focusing on the overall operation of the FHT setting and clinical issues, and clinical meetings specifically dedicated to the discussion of diabetes care provision to people with mental illnesses. These observations occurred concurrently with interviews, observations, writing, and preliminary analysis of my data. Preliminary findings shaped and guided further observations and interviews.

Field Notes

Emerson et al. (1995) state that field notes are essential to writing a sound and true ethnography as they provide a context and deeper meaning of data that may not be available through interviews. In this research project field notes included handwritten jotted notes written on the spot, reflections of observations documented shortly after the sessions, and notes subsequently typed up immediately after or within several days following my observations (see for example, Appendix XII: Field Note Example). During my analysis, I divided the field notes into the following sections: (a) generic field notes pertaining to the clinical care of patients with severe mental illnesses and diabetes as observed during on-site visits and at group attendance; and (b) my personal reflections both in-the-moment and following my observations in a type of memo. These observations, reflections, and memos provided a context, and a point of frequent
reference, when coding interviews, analyzing transcripts, and reading and re-reading my analysis. They also served as my reflective references to keep me grounded in my data.

Participant Interviews

In keeping with ethnographic inquiry, semi-structured, one-on-one interviews were employed to answer objectives of this study. I deliberately adopted the position of a novel explorer, and asked respondents to assume the role of a mentor and knower to teach me about diabetes care management. With this strategy, I strived not only to minimize the power differentials between participants and myself, but also to use a friendlier and more conversational style of interviewing. I employed this approach to encourage participants to move beyond jargon or expert terminology, which might obscure their real activities or work. In turn, this allowed me to remain focused on the actual daily practices in which people with severe mental illnesses and diabetes engage. This data later became an integral part of my data analysis.

I collected data in several stages. First, I started with those diagnosed with severe mental illnesses and diabetes specifically focusing on what they do and how they do it in relation to their diabetes care as lived in their daily realities. My on-site observations augmented those interviews. Building on understandings that emerged through those interviews and observations, I moved to interviewing health providers with the aim of understanding how their practices of providing care were organized. This provided a starting point for my broader data analysis.

Patients with Severe Mental Illnesses and Diabetes

Several issues were considered while interviewing people with severe mental illnesses and diabetes. Literature that has examined the inclusion of people with mental illnesses as study participants has identified several participant- and researcher-related factors that may affect
interview outcomes. These include patient medical issues such as the presence or severity of clinical symptoms, and medication side effects as potentially affecting interview processes and outcomes. Mental illness has been perceived by some researchers to impact participants’ articulation and recall of their experiences, thus potentially compromising ‘true’ data (Moyle, 2002). Other researchers question the ethics and suitability of researching this population all together (Usher & Holmes, 1997). Interviews may be stressful for participants, evoking feelings of frustration, anger, and confusion, which is especially significant in case of people with mental illnesses where stress on its own forms the basis of the contemporary explanatory framework about the illness (McCann & Clark, 2005). Finally, an interviewer’s lack of understanding, or even fear, of this population may also affect the conduct and outcome of interviews (Dworkin, 1992; Fontana & Frey, 2005).

I have been working in the mental health field for over sixteen years in various capacities, including those as a clinician, scholar, and advocate. Through decades of clinical and academic work I have developed a particular level of familiarity and comfort working with this population. As an interviewer, I remained mindful of the relationship between vulnerability and stress. I recognized that some participants may find the interview stressful, or that psychiatric symptoms might interrupt the process of an interview, as did happen in one case. I employed several strategies to minimize the level of stress for potential interviewees. First, all interviews were conducted in a quiet room to minimize distractions and to provide a relaxing atmosphere. Next, before the start of each interview, I informed participants that should they experience any distress that they could stop the interview at any point. Third, I closely monitored patients’ overall presentation, and checked frequently with them whether they were experiencing any distress. Finally, I encouraged them to talk freely, and to share only the information that they felt comfortable with disclosing.
Thorough this project, I remained cognizant of the hierarchical difference in my social location whereby I remained a clinician and the one to question them. However, I did use several techniques to minimize this impact, specifically the one offered by DeRoche and Lahman (2008). First, I tried to maximize participant’s control over the interview by having an open approach to interview questions. Related to this, I also encouraged participants to share whatever information they considered relevant. At all times, I attempted to be mindful of my verbal and non-verbal body language (DeRoche & Lahman, 2008). I also maintained rigorous reflexive notes to flag personal assumptions and understandings (see Appendix XIII: Reflective Note Example). Next, I developed my semi-structured interview guide using Finlay and Lyons (2001) suggestions. For example, I used a minimum number of words and avoided complex phrasing; I situated questions within a specific context from the participant life (e.g., asking about their ‘regular day’). I also allowed an introductory period (warm up) to establish rapport and utilized re-phrasing and probing questions, thus allowing participants to develop their own narratives.

In line with other reports in a literature on methodological issues on interviewing people with mental illnesses (Hutchinson, Wilson & Wilson, 1994; Murray, 2003; Patton, 1990), I found that participation in research may provide tangible benefits for those diagnosed by allowing them to share their stories not accessible otherwise. Specifically, I discovered that focusing on patients and providers specific ‘doings,’ that is specific activities they engaged into in relation to diabetes management, may be a beneficial technique when interviewing people with mental illnesses as it allows a switch in focus from me as an interviewer to them as experts in their descriptions of their experiences. Namely, I explicitly assumed the position of a “learner” and invited respondents to undertake the position of a “mentor” to teach a novice individual about diabetic management practices. It is noteworthy that the technique used was employed to put
participants on ease and to facilitate a conversation, not to impose artificial blurring of power
differential between myself and my respondents. This strategy allowed me to access practices
not visible otherwise, and for participants to share their experiences in a more casual and
engaging manner.

Health Professional and Administrator Interviews

Health professionals and administrators were interviewed following an evolving understanding
of diabetes management from the perspective of diagnosed participants. In line with critical
qualitative inquiry where ontological understanding of phenomena is viewed as being bound to
the broader socio-economic-historical context, health professionals and administrators who
could comment on aspects of the organization and care provision, and were involved directly or indirectly in the diabetes management care of people with severe mental illnesses, were also interviewed. Health care providers’ interviews were conducted in a similar manner and also aimed to explore routine practices performed by providers in relation to diabetes management.

Documentation

The documents in this study were treated as a secondary data building more of a frame diabetes
care occurred within. Documents were largely written texts that I have encountered in the field
setting either through my interviews with participants or during my field observations. Clinical and regulatory documentation was used to gain background knowledge needed to reconstruct practices of diabetes management I observed. Specifically, (1) the electronic medical chart, which is embedded into it medical form on reporting of diabetes medical indicators (see Appendix XIV: Diabetes Flow Chart), a medical document outlined major medical indicators to be collected and reported, such as blood glucose levels, glycated hemoglobin (A1C) levels,
patients’ weight to height ratio calculated through BMI, blood pressure indicators, and information related to substance (e.g., cigarettes and alcohol) use; (2) documents determining patients’ entry, such as referral forms (see Appendix XV: Referral Form); (3) textual documentation focusing on assessment of patients’ progress in their diabetes care, such as ‘My Goals’ card (see Appendix XVI: My Goals); and (4) FHT annual reports (see Appendix XVII: Program and Service Details) which are main tools of reporting to governmental bodies and therefore are major accountability means for FHT, all served as supplementary sources of data in this research study to better understand how diabetes management services were developed.

In this study, a particular document, such as the *Conversational Map* (see Appendix I: Conversational Map) is of particular importance as it was used by both patients and clinicians in the setting as a guide in diabetes care. The Conversational Map and accompanied it the Conversational Map Manual is a visual tool introduced (currently in patenting stage) and promoted by the pharmaceutical company, Eli Lily, as a textual representation of current knowledge on diabetes and its management as presented in Clinical Practice Guidelines (Harper et al., 2013). The Conversational Map evokes an image of a marathon that is a road with a start, followed by main reference points which describe how and when diabetes management tasks are expected to be completed, concluding with a ‘finish line’ with ‘achieving goals’ in successful diabetes management. These ‘stops’ include: (1) practices around knowledge and skills on blood glucose levels (BG) monitoring; (2) ‘facts and myths’ based on medical knowledge about diabetes, such as factors that impact diabetes and the risks associated with insufficient diabetes control; (3) healthy lifestyle goals towards the end of the ‘marathon line’ and which focuses on proper eating, portion control, and regular exercise; and (4) regular foot care and check-ins with clinicians. The symbolic ‘final crossing’ of success through the red ribbon with applauding bystanders reflects the assumption that if and when all ‘stops’ are properly completed; diabetes
management is successfully achieved. In this project, the Conversational Map was fundamental to my analysis in that it provided an entry point to access and understanding of how diabetes management is presented to and experienced by those diagnosed with severe mental illnesses.

**Data Analysis Procedure**

The process of analyzing this research data was recursive and iterative (Gulati, Paterson, Medves & Luce-Kapler, 2011). My analytical journey began before I entered the field and continued throughout the writing process. I adapted my research as I progressed, and my analytic focus has shifted, as new knowledge was identified moving me towards new discoveries. In line with other social science scholars’ work, such as Taber (2010), Bischoping (2005), and Joan Eakin (Personal communication, October 1, 2013) who argued that meaning is constructed through interpretation in both process of data collection and writing interpretations, my data analysis was not limited to coding. It progressed into my final writings, as I made my analytical decisions on what to include or exclude in my final interpretation, based on my theoretical lens and on research objectives of this project. Therefore, my data analysis also did not stop with coding; rather it became an ongoing, theoretically informed, and interactive process throughout this project. Writing my theses was also an important part of my analytical interpretations, as I explored my lenses as I wrote, added to, deleted from, and reworded my ethnographic narrative, where my analytical interpretations become constructed through my engagement with data and written text of this thesis in a systematic, but not standardized manner. Data analysis involved collecting, recording, separating, and interpreting the multiple data accessed to understand diabetes management in the context of severe mental illnesses as a whole. Different types of data were collected, and even though all data were important in analytical interpretations, not all data were analyzed with the same intensity or weighted the
same. In this work, I do not map findings from providers’ and administrators as this knowledge is already re-presented by the tool of the Conversational Map. I made this analytic choice following discussion with my PhD supervisor wherein I realized presenting narratives from both patients and providers dislocated my patients’ stories. My aim was to keep analytical interpretations on those of patients as main subjects of this work.

All interviews were audio taped. In this work, I adapted Tilley (2003) stance, who argued that transcription is an extensive interpretative and analytical process, and therefore it is advised whenever possible for researchers to transcribe tapes themselves to move beyond versions “of the objective transcriber who has an unassuming presence in the research process” (p.770). Although it is common practice in academia for somebody other than a researcher to transcribe taped recorded interviews, I personally transcribed all interviews verbatim, keeping participants’ ways of talking, retaining grammar, pauses, and slang. I used the express scribe professional software (NCH software), which facilitated managing the speed of converting audio material to a transcribed version of participants’ verbal accounts. I chose to transcribe interviews on my own not to present a “truthful application of some objective reality (Tilley, 2003, p. 751), but rather to focus on transcription as a part of data analysis interpretative process, where my theoretical position directly framed my analysis. As Lapadat and Lindsay (1999) suggest, analyses and deeper understanding of data occur during the act of transcribing. Indeed, over the process of transcription I have realized that transcription of recordings cannot be neutral, as I made decisions around what to include and what to exclude. For example, I decided to keep colloquial spelling and pronunciations of my participants, instead of correcting them as I aimed for reflexivity and transparency in my work where it is clear that “transcription of a text always involves the inscription of a context” (Bucholtz, 2000, p.463).
Next, all transcripts were imported into QSR NVivo 10 software (Qualitative Solutions Research International, 2012) to organize and analyze large segments of data, including interview transcripts, field notes, memos, and excerpts from collected documents. NVivo was used to identify broadly key themes and patterns in diabetes management in people with severe mental illnesses. Data was coded in relation to the Conversational Map through comparing and contrasting the main points on the map against patients’ personal ethnographic accounts as they related to these particular points. I used broad codes first as a way of labeling aspects of data, separating specific elements and sorting data into distinctive categories (LeCompte & Schensul, 1999; Walsh, 2003). For that, I used the Conversational Map as the guiding principle and mapped units identified from my data (for example, codes such as “food”, “experiences with medications”, “daily routine”, etc.) onto it (see Appendix XVIII: Conversational Map Mapped Coding). This level of analysis involved a line-by-line review to organize items into free nodes (a shorter meaningful excerpt). The list of these free nodes was then examined to establish codes (conceptual label for a group of similar items), which were constantly reviewed, updated and applied as the data analysis progressed. I first started with line-by-line coding, and then followed with second-level coding as mapped onto the Conversational Map, which continued to be my sensitizing lenses (Denzin & Lincoln, 1994). I then organized codes and categories hierarchically as mapped onto Conversational Map, where larger codes corresponded to ones on Conversational Map, and then patients reported experiences forming second-, third-, and so force-level coding (see Figure 1: Example of Branching Categories in Data Coding). These codes identified from those diagnosed were then reconciled into broader themes upon which my analysis rests.

**Figure 1: Example of Branching Categories in Data Coding**
The analysis of ethnographic data was a multi-step process that began with the Conversational Map as an organizing concept. I then compared and contrasted the ethnographic accounts against the images, strategies, and medical understandings embedded in and represented by the map. This led to my discovery of the inadequacy of the Conversational Map to capture the fluid and uneven nature of diabetes management by people with severe mental illnesses; specifically, its inattention to context complexity and relationship reciprocity. For example, in the Conversational Map dietary choices are presented as an important aspect of self-management. However, in accounts provided by patients, both access to and control over food choices was problematized. This provided a challenge to the assumption that food choices were an issue of patient adherence to dietary regimes. Patient adherence, in my developing analysis, became formulated as three-dimensional. I linked this to the idea of detours, rather than “adherence,” which may be a more accurate representation of diabetes self-management in people with severe mental illnesses. According to this conceptualization, there is a complex interplay between personal experiences and the overall landscape in which people’s lives are embedded.
Quality and Rigor

Currently, there is debate on how to assess quality and rigour in qualitative research. Some scholars dismiss questions of validity, reliability and generalizability as “oppressive positivist concepts that hamper a creative and emancipatory qualitative research,” (Kvale, 1995, p. 231); and more suitable for quantitative research (Kvale, 1995; Denzin, 2010, p.424; Eakin & Mykahovskiy, 2003; Eakin et al., 1996). Many others have suggested other criteria for evaluating qualitative research inquiries and ethnography in particular (Denzin, 2010). Guba & Lincoln (2005) advocate the usefulness of concepts such as trustworthiness, credibility, dependability, and confirmability to assess the quality of qualitative research inquiries. Richardson (2000) has suggested key attributes by which we can evaluate the quality of ethnographic research. They take the form of the following 5 questions that can be asked of a study:

- **Substantive Contribution:** "Does the piece contribute to our understanding of social-life?"
- **Aesthetic Merit:** "Does this piece succeed aesthetically?"
- **Reflexivity:** "How did the author come to write this text…Is there adequate self-awareness and self-exposure for the reader to make judgments about the point of view?"
- **Impact:** "Does this affect me? Emotionally? Intellectually?" Does it move me?
- **Expresses a Reality:** "Does it seem 'true'—a credible account of a cultural, social, individual, or communal sense of the 'real'?"

Other criteria for evaluation have been outlined by Tracy (2010) who suggests eight markers to appraise the quality of ethnographic research: (1) worthy topic; (2) rich rigor; (3) sincerity; (4) credibility; (5) resonance; (6) significant contribution; (7) ethics; and (8) meaningful coherence.
In this work, I chose a combination of criteria resembling the ideas of several prominent social science scholars in relation to evaluating ethnographic inquiry. Specifically, I use Holstein and Gubrium (2004) concept of *conceptual applicability* to assess how findings of this research project are applicable (i.e., transferable) to different contexts and populations when they share similar patterns and characteristics. I also use Carter and Little’s (2007) concept of verification of knowledge claims to assess this project validity and rigor. Finally, I apply the concept of critical subjectivity and credibility (Giacomini, 2010; Tracy, 2010) as merits of evaluation for this research project.

**Conceptual Applicability**

From a public health perspective, the ability to apply findings to a broader context and different populations is important. It is generally accepted by many qualitative researchers that “generalization is neither possible nor desirable” (Denzin, 2010, p.424). Contrary to statistical generalization where the discussion concerns representation and generalization through numbers, Halkier (2011) argues that qualitative generalization should be specific and context bound rather than universalized; some refer to this as transferability. In line with that, findings in this study are “analytical generalizations […] produced by context-bound typicalities” (Halkier, 2011, p. 788). The findings generated from this dissertation allow the transfer of identified concepts to similar contexts, circumstances, and populations. For example, these findings may be applicable to individuals with diabetes who do not have a severe mental illness, but who experience other forms of social marginalization such as poverty or racism, as they too are also often resource-deprived. As such, the context and relationality implications from this study may be useful for patients, clinicians and policy makers when determining which policies
and practices could be modified to ensure more positive experiences of diabetes management across a broad range of patients, as well as their application to the management of other chronic illnesses.

**Verification of Knowledge Claims: Internal Coherence**

In line with the social science thinking, personal experiences cannot be fully understood unless analysis is grounded in peoples’ actual activities performed within particular lived contexts (Spivak, 1993). This project accesses personal experiences by focusing on the empirical activities in which participants engage. As such, data analysis in this project builds on representations and understandings of the experience and materiality of diagnosed participants. Assessing the quality of any research fundamentally lies in the validity of its claims, and the adequacy of the representation of the social events and practices to which the research project refers (Freebody, 2003). To achieve this goal, I strived to present interpretations along with my analytic decision making process wherever possible (Joppe, 2000 as cited in Golafshani, 2003, p. 1).

**Critical Subjectivity**

In biomedical research, what the researcher brings to the project, including interpretations informed by background and identity, are treated as bias that needs to be eliminated from the design, rather than being a valuable component of it (Maxwell, 1996). Contrary to this position, social science encourages displacing researchers’ authority, and holding researchers accountable by requiring explicit research project goals, intentions, and procedural principles, which is referred to as reflexivity or transparency (Walby, 2007). In this line of thinking, critical subjectivity is a way to enhance the credibility of research (Giacomini, 2010; Tracy, 2010). This
research study is based on the premise that one’s identity and experience are not to be eliminated, but rather should be explicitly incorporated in research, as “any view is a view from some perspective, and therefore incorporates a stance of the observer” (Maxwell, 1996, p.29). I conducted this study with the understanding that I am a central figure who influences the collection, selection, and interpretation of data, and my own social location, biography, worldview, class, and skin colour shaped how this research project proceeded and analysis was carried out (Finlay, 2002). Building on Eakin and Mykhalovskiy (2003), I approached subjectivity not as a bias to be eliminated or reduced (or at least confessed), but as something to be used actively and creatively throughout the research process. According to Reason (1988), one should exercise the “quality of awareness in which we do not suppress our primary experience; rather we raise it to consciousness and use it as part of the inquiry” (p.12), which is referred to as critical subjectivity. Therefore, I used my subjective knowledge, such as my clinical understanding around disease management previously developed through my training and clinical interactions, and my academic knowledge informed by graduate studies in social science and behaviour. I also used reflective practices, such as memoing, and consulting with my committee members, to ensure I maintained a critical stand towards my writing.

Summary

This chapter outlined the research design for this project, beginning with ethical considerations and negotiating access to the research site. I followed with a description of the project’s theoretical framework and methodological rationale, focusing on sampling, data collection, and data analysis. I concluded with a discussion on study rigour, and the strategies I utilized to ensure quality of this project.
Chapter 5: Findings. A Roadmap of Diabetes Management

This chapter analyzes diabetes management care in people with severe mental illnesses through investigation of the material and empirically accessible events in their lives by paying close attention to their daily practices of diabetes management, and listening to their stories. As in Brian’s vignette, my findings tell a story of complexity, a combined narrative filled with challenges, stresses, and obstacles as patients with mental illnesses deal with their diabetes, but also one of empowerment and creativity; the story which goes beyond a biomedical view of compliance and self-management.

Introduction

In this section, I report explicitly on the experiences of patients diagnosed with severe mental illnesses and diabetes as elicited through my one-on-one interviews and observations. In this chapter, I frame my results and analysis vis-à-vis the Conversational Map. As described in a previous chapter, the Conversational Map is a visual tool employed by clinicians in the primary care setting in this study; and is a representation of a biomedical discourse currently dominant in the field of diabetes management. The Conversational Map captures the main biomedical and behavioral understandings of diabetes management, which currently define clinical practices and public health policies. During my observations, I found that the Conversational Map is used as a guiding instrument by clinicians in their psycho-education groups with patients, and is usually placed on a table with clinicians and patients seated around it. During discussions with patients, clinicians often point out particular aspects or visuals on the Conversational Map, in order to direct the conversation with patients.
In this chapter, I begin with *Part One: An Entry Point*. I map how individuals with severe mental illnesses come to know their diagnosis of diabetes, and what is involved in entering into and receiving diabetes care.

I then follow with *Part Two: A Diabetes Roadmap*. This builds on the Conversational Map visualization of diabetes through a roadmap with an entry and an exit, and reference points in between, such as: (1) experience and understanding of diabetes; (2) feelings and emotions; (3) potential negative consequences; (4) recognizing and managing symptoms; (5) lifestyle change, and (6) a finish line. In this section, I will compare and contrast experiences of diabetes management as biomedically understood and visualized in the Conversational Map, and as experienced by those diagnosed with severe mental illnesses.

I conclude with *Part Three: Chapter Summary*. Here I summarize findings, which problematize the schematic understanding of diabetes management represented in the Conversational Map in relation to the complex and context-oriented diabetes management experiences identified by participants. I argue participants’ experiences can be better understood through the application of a perspective, which fosters movement beyond idealized concepts of self-care and brings forward new knowledge regarding the realities of people with severe mental illnesses, aspects explored in more detail in Chapter 6.

**Part One: An Entry Point**

**Mapped Realities**

On the Conversational Map, the entry point to medical care is represented as an open road where the patient faces a board describing diabetes as “a disease in which a body does not make
enough of insulin, the insulin does not work properly, or both. This can cause the amount of glucose (sugar) in the blood to be higher than normal.”

On the Conversational Map, there are no obstacles, gates or other barriers that preclude one from entering this road, aka receiving medical care. The road on the Conversational Map is well maintained, smooth, and inviting. The woman character, who visually represents a patient with diabetes, is situated at the entry point of the Conversational Map facing the road, looking cheerful, and appears ready to start her journey. There is neither information on how and by whom this road is maintained, nor about the woman entering it in relation to her previous life course and current living circumstances prior to this entry point. The Conversational Map presents the road as readily accessible and well maintained, suggesting an unproblematic tour on even grounds.

Participants’ Experiences

To receive diabetes services, a formal diagnosis must be made. Yet, on the Conversational Map, the process of receiving the diagnosis is not represented, suggesting perhaps that the matter of diagnosis is immaterial to the journey. However, findings derived from patients’ interviews, health care providers and administrators, and on-site observations suggest differently. Instead, the diagnostic entry point for people diagnosed with severe mental illnesses and diabetes may be quite complex. For diabetes care services to begin, several requirements must occur beforehand. First, the formal diagnosis of diabetes mellitus must be assigned by a medical professional, and second, initiation of the process of access itself through referrals or transfers must follow. These require a complex set of practices being put in place, far beyond the straightforward entry portrayed on the Conversational Map. Further, an entry point for this population also varies significantly depending on the way diagnosis was discovered. The majority of participants in
this study were diagnosed with diabetes as a random clinical discovery, specifically through medical crisis or following routine medical tests, which triggered significant variations in responses from health practitioners prior to the formalization of diagnosis and facilitation of the referral process.

Diagnosis Stage: A Random Discovery

In this research study, participants had been living with mental illnesses for a substantial number of years, with some participants being diagnosed with psychiatric conditions decades prior. At the time of interview, participants were well acquainted with their mental illnesses, knew their symptoms, main treatment options, and were familiar with what clinicians expected of them. This gave patients a particular level of expertise in how they managed their mental illness, and therefore a particular level of mastery is reasonable to assume. Despite this, a diagnosis of diabetes was reported by some as unexpected, often frightening, and disruptive, and at times as confusing. For example, Participant 03, a 49-year-old woman of color with schizophrenia, was diagnosed with diabetes following a medical crisis. She had been attending an outpatient recreational swimming program when she started feeling nauseated and dizzy:

P: I was there [for the outpatient program] I was swimming, and I [started seeing] stars and got in trouble... I come out from the pool as soon as I feel myself as going ‘ewwww’ [demonstrates how she felt dizzy by rolling her head]. [...] I had a nurse saying: “you know, you sick of diabetes.”

In contrast to Participant 03’s discovery of a diagnosis of diabetes as a result of a medical emergency, several respondents reported receiving a diabetes diagnosis as a result of ad hoc findings on their blood work. Even in these cases, the formalization of diagnosis did not take place immediately, but fell under the trajectory of higher risk for its development. In such cases, patients with mental illnesses were offered no formal services or care in relation to their
diabetes, since the formalization of the diagnosis has not occurred at that point. Delayed care occurred in the case of Participant 10, a 53-yo white man diagnosed with bipolar disorder and diabetes, which stands in a significant contrast with the pictured view of an open road visualized through the Conversational Map. He explained:

P: Well, before [the diagnoses of diabetes] my [health] history always been my cholesterol and blood sugar sometimes were normal and sometimes not. It’s kinda been like up and down. […]. For me sugar and things like that, don’t good for you, to eat all that sugar. I know that for years, and years, and years, since I was an adolescent. I knew about eating, about this place [family health team clinic] since a long time, but, I wasn’t practicing, I didn’t feel the need for it, because my cholesterol was always checked. Numbers wasn’t too high, until recently, until last two to three years straight, when my cholesterol was high, sugar was high.

I: [During] those two years were you doing anything for your diabetes?

P: no, I didn’t. I didn’t have any symptoms, just have been recently I found. [It] was just a random test they gave me for the blood sugar test. […] I did a blood test, yeah, because my cholesterol was very high, was up to chart, so, that’s changed everything.

I: and what was your reaction?

P: I have to change, I guess. You know, I want to live longer. (Sighs) […] I used to read a book Sugar Blue, I’ve known about sugar and how it affects...but it wasn’t too much of an issue for me, because I was fit, nothing really bothered me till recently till I am, like, older. I did my annuals [referral no annual physical exam], this is only by accident that I found out.

Both examples demonstrate that in order to receive diabetes care, one had to be formally diagnosed, which is of course similar with any other medical condition. However, what these examples also show is that diabetes awareness and prevention are not a routine part of care received, even though patients are considered at high risk by clinicians. This develops an
environment in which for patients with mental illnesses the diagnosis of diabetes often remains a
discovery, even though they are tested for it, and this diagnosis is rarely a surprise to the
medical provider, all likely due to the fact that preventive aspects located outside the domain of
biomedical diabetes care practices.

Service Provision Stage

The Conversational Map visualizes the point of entry to diabetes care services as an open road
with no obstacles, which presumes that all individuals are equally welcome, and unencumbered
to walk the road (that is, to access diabetes care). Yet participants’ narratives identified that
entering diabetes care relied on their prior connections to mental health services and medical
providers, reflected the quality of these connections, and relied on patients’ individual abilities
to navigate the system.

To demonstrate, the overwhelming majority of participants in this project reported the process
of entry as facilitated. This means that their clinical information, which is a set of particular
expertly chosen characteristics (e.g., name, address, gender, diagnosis, medications, etc.) usually
organized in a text format, was sent from one clinician to another through the use of a referral
form (see Appendix XV: Referral Form). The textual representation of the patient through the
process of referral either by means of fax, email, or phone triggered the formalization of the
diabetes diagnosis to facilitate further access to care. Without this process, individual access to
care is problematized. Indeed, patients themselves described their experiences entering diabetes
care as a transfer or a referral. Participant 07, a 66-year-old white woman with schizophrenia,
explained how she came to receive diabetes care at the family health team setting:
P: [mental health team] transferred me. I was just sitting there [at the psychiatric hospital waiting for an appointment], they [team] send me for blood work, the urine test. I had to go to the lab […] every month, they booked blood work.

However, in this study I identified that entering diabetes care through the process of referral was not the only mechanism. For some patients, accessing diabetic care entry reflected their personal motivation and abilities to navigate the health care system. For example, participant 10 had recently moved homes, and had to change his family physician as a result. He explained:

P: I was looking for somebody closer [to my house]. I just walked in [to the hospital clinic] and they gave me a phone number [for the family health team clinic] and that’s how I get in touch with them. […] [The family health care team] called me, she [physician] did an assessment on me and from then on, she’s been my doctor.

These findings suggest that, contrary to the linear logic of the Conversational Map, for people with severe mental illnesses, the process of entry to diabetic care is not straightforward and unproblematic. Instead, it is complex, defined by patients’ previous connections to the health system and health providers, and reflects individual abilities and skills in navigating the system. This variability is important to understand, as it suggests that the biomedical logic of the Conversational Map (unfettered individuals simply accessing diabetic services) may not be applicable to those with severe mental illnesses.

Part Two: Diabetes Road Map

In clinical practice, diabetes management for people with severe mental illnesses is viewed through the lens of biological/physiological dysfunction and lifestyle behaviors, necessitating regular clinical attention and assessment of particular clinical outcomes. Consequently, the Conversational Map depicts the journey of diabetes management as a roadmap, where one’s
journey is along a clear well-defined path, on even grounds with distinct features, and a straightforward destination (e.g., exit).

STOP ONE: Experiencing Diabetes

Mapped Realities

The Conversational Map as a visual representation of clinical practice guidelines reflects the understanding of diabetes as a medical condition with physiological deficits, which are treatable with a combination of pharmaceuticals and lifestyle behaviors. Following the entrance, the road continues along with a wide-open path, with pictured terms ‘insulin, pancreas, blood glucose, liver, fat, muscles,’ located along the road on the right, and a trio of ‘A1C & Blood Glucose Levels+ Blood Pressure+ Cholesterol’ located more centrally on a board. The pictures echo the biomedical understanding of diabetes which is written up as a disease of insulin dysfunction, specifically related to ‘insulin,’ ‘pancreas,’ ‘blood glucose,’ ‘liver,’ ‘fat,’ and ‘muscles.’ Next, the road progresses towards the ‘Facts and Myth’ section. The ‘Facts’ section is located at the upper left corner of the Conversational Map. It houses a beautiful fountain with clean water where people cheerfully gather around. The ‘Myths’ section is located further left, and is represented by an abandoned grey garbage bin hidden on a side road near the woods.

Participants’ Experiences

Patients in this research study recounted diverse encounters of diabetes management experiences, which shaped their understanding of diabetes and its management. In addition to understanding diabetes within its physiological/behavioral merits, patients also demonstrated an understanding of diabetes as social and contextual.
Diabetes as Dysfunction

In line with dominant biomedical understandings, respondents in this study described diabetes as “in your blood” (Participant 01, a 61-year-old man of color diagnosed with schizophrenia) and a consequence of “not taking care” in relation to lifestyle choices (Participant 10). The majority of interviewed participants demonstrated awareness of the main biomedical assumptions in relation to diabetes causes. To illustrate, Participant 01, who is living in supportive housing, repeated what he had been told by health care providers:

P: If pancreas does not give insulin, then [sugar] is in the blood. […] The pancreas is not working. They [clinicians] told me is that pancreas not working that produce that amount of insulin. That’s what they said: it’s in the blood.

Learning about diabetes as a deficiency was also an important theme identified through my on-site observations and informal interviews with health providers. During a field observation, I recorded:

9:40 a.m. We are in a boardroom. Three patients, all men, one case worker (doing some notes in her agenda), newly assigned to the program registered nurse, and another registered nurse I work with.

The new registered nurse starts with ‘breakfast’ preparation by providing oatmeal, bagel, and water to all patients.

9:42 a.m. The nurse practitioner comes in, approaches one patient, talks about medications to him and then leaves […]. She comes back shortly carrying medications in a tube, takes some of them out and places them on a napkin in front of a patient, then instructs him to take them, and then leaves again. Patient dutifully takes medications from the napkin in front of him.

9:46 a.m. The group starts with the nurse (the one I work with) using the first set of Conversational Maps from the package, the one focusing on a description of diabetes.
This part corresponds with step one in the educational manual. The Map describes what diabetes is, what kind of complications may occur, and what organs are affected. The nurse also uses two tubes filled with a red fluid and with small white spheres locked inside of it. When she turns the tube, white spheres in one tube moves fast, while in the other they move very slow, this aims to represent how blood sugar affects blood flow in a blood vessel in real vessels inside of one’s body. [...]. Patients observe but do not facilitate further conversation. [...].

The group then continues with another nurse talking about nutrition. She [talks about] ‘food categories’, and ‘nutrition.’ The nurse I work with […] looks up to patients, and interjects, trying to simplify the language. She reframes it into ‘food groups,’ and ‘diet.’ The conversation continues to focus on a “balanced meal plate.” The nurse is pointing to the Conversational Map, and using her hands demonstrate the amount of vegetables, starch, and meat which patient is supposed to consume. […] One patient starts describing how he loves to have a hot soup. The nurse listens, acknowledges that soup is “good.” Interestingly enough, soup does not fit in in any of available boxes, so the nurse continues with conversation. The nurse distributes ‘food cards’ from the Conversational Map kit and asks patients to place them under proper categories on the Map. All three patients are readily participating ‘placing’ proper food categories in their proper places. Patients seem to have no issues with understanding the category groupings. They are aware of “good” vs “bad” food choices, and overall demonstrate a particular level of comprehensive knowledge around diet in diabetes management.

10:00 a.m. The nurse I work with moves into the next section of the Conversational Map, particularly ‘foot care.’ She speaks while standing on the right of the Conversational Map, which is placed on the table. She then continues with ‘cards’ that demonstrate different problems with feet which need to be checked. She talks about potential complications, and concludes with the necessity of following with a regular foot exam.

Patients are mostly silent in the group, answering questions when asked, and sharing at times their own thoughts very briefly. They nod a lot. The nurse leaves to bring appointment cards for the next appointment.
10:05- The group session is completed. However, everybody remains seated waiting for the nurse to come back and bring appointment cards. She comes back, approaches each patient and explains when the next appointment is. One patient asks whether he can go now [Memo: asking permission?], and the nurse responds that group is over, and everybody is free to leave.

Similar observations were made at a metabolic clinic for another group, when the discussion evolved around negative consequences of diabetes:

This group is dedicated to foot care, specifically the importance of checking, monitoring, moisturizing and attending a specialist on regular basis. Two nurses, assistant, and physician are also present in the room. One patient seems to be knowledgeable in diabetes management and is aware about the consequences, and how to handle tasks (he is ‘finishing up’ sentences after a nurse). Second patient presents in a way that clinicians usually describe as ‘distractive’: he interjects a lot, he talks loudly, he moves a lot around, and laughs. The nurse is visibly annoyed and tries to get him back ‘on track’ by reminding him of group rules and asking him to listen. […].

Shortly after the group starts, a pharmacist comes in. He is invited to demonstrate a glucometer, and encourages patients to use it. One patient has one and knows how to use one. The “disruptive” patient refuses. […]. Immediately following his refusal, the nurse turns to the physician and tells him that this particular patient refuses to take foot exam as well. (Everybody is still sitting in the room, including other patients, and personnel). The physician addresses this patient directly and asks why, and tries to convince him to take it. The patient looks uncomfortable, he does not look at the physician, and mumbles that he is ‘not that important’ and does not want his feet to be checked. The physician corrects him right away and tries to reassure that his statement is not true, and “this is what nurses are for,” and “to serve” the patient. The patient appeared to be uncomfortable but continues to firmly refuse. Then the physician turns to the nurse and tells her that this patient did a foot exam with him previously. [Memo: at this point I started to wonder whether he may felt embarrassed or ashamed, had negative experiences in relation to medical procedures in the past].
The physician, and the pharmacist ask whether anybody has any questions, then thank everyone and leave. Another nurse, two patients, and I stay in the room. The discussion continues on the importance of proper footwear (e.g., good shoes), and wearing socks (e.g., “buy cotton”) all the time. The group discusses the material (e.g., “cotton” preferably) and accessibility (e.g., price, where to buy, how to figure out where to buy them, how to care for them to last longer). [...] The session ends with the nurse giving appointment cards to each patient to remind them about their next appointment in three months.

These observations suggest that knowledge about diabetes as a deficiency, and potential negative consequences associated with it, is an important conversation in clinical practices. Time, personnel, and resources are dedicated to ensure patients are informed of these medical aspects, with the underpinning rationale that better knowledge will translate into better self-management through regime compliance, and ultimately will lead to better clinical outcomes.

Experiences of Diabetes through the Lived Realities

The full range of experiences associated with diabetes and its management experienced by patients with severe mental illnesses was not addressed by health care providers through education. While participants relayed personal stories that described a heightened sense of isolation and anxiety about the future that framed and shaped their current experiences with diabetes management, along with narratives of resilience to overcome them, this complexity was not clearly depicted in the Conversational Map.

Participant 01 demonstrated good biomedical knowledge around diabetes management and was closely compliant with medical recommendations. However, despite his close involvement with biomedically defined diabetes care aspects, when interviewed on his decision-making behaviors around diabetes management, he also connected his behaviors to his complex relationships and connections with others, including members of his family, friends, and community. His
diabetes decision-making behaviors were associated with his lack of support within his present context of living: that is, as a psychiatric patient, divorced, unemployed, living far from his family, with church being the only support he has access to. This context formed his need “take care of it,” which effectively assigned him full responsibility for his diabetes management, since no one was available to support him through it:

P: Because I care…I know my father had it. I want to take care of it. If you don’t take care it would kill you. […] it kills, so…I decided I do not want to die and [took care of it].

Similarly, other participants identified a connection between their previous experiences and current decision-making behaviors. For example, Participant 04, a 54-year-old white man with schizophrenia, reported on severe complications of diabetes in his family member who nevertheless enjoyed a better quality of life than he was projecting for himself, an experience which molded his present behaviors in relation to the ways he engaged in his diabetes management:

P: [My grandfather was numb] from his waist down, he couldn’t feel [his legs]. He lived in a country where you couldn’t [quickly access physicians]. He had to go to the [city] to give his urine [for diabetes testing]. [But he was] ninety years old, celebrated fifty years of marriage, and had twelve children. He used to walk from chair to the window [to see outside] at ninety years old, [and now] look, [I am] forty years old [without family].

These patients demonstrate that understanding or expectations of diabetes are shaped by their lived realities, which in turn reflect their previous experiences as developed within a particular context (e.g. even though this patient didn’t have the extent of diabetes complications as his grandfather did, he still unfavorably compared himself to his grandfather because he was socially isolated). Therefore, patients’ experiences with diabetes management cannot be solely defined through attention to its biophysiological aspects, as patient experiences and
understandings are complex and are formed on the grounds of their past, framing and shaping their present decision-making behaviors in relation how diabetes management is executed. This stands in stark contrast with the understanding embedded into the Conversational Map, that is, that medical complications should be prioritized, and addressing them firsthand should be an important focus to facilitate patients’ decision-making behaviors towards compliance and self-management. Contrary to this, my findings suggest that patients’ behaviors and expected health outcomes are also influenced by patients’ experiential knowledge, which forms a particular relief in which future behaviors occur. Experiential knowledge is equally if no more important in understanding how decisions around diabetes care are made by this population.

Diabetes as a Chore

Next, I identified that patients’ present contexts, including challenges and resources formed their experiences with diabetes management. In clinical practices, diabetes self-management focuses on close attainment with clinical recommendations, specifically compliance with blood sugar monitoring, pharmaceuticals, and lifestyle behaviors. Success is equated with the consistency of performing recommended actions, evidenced by particular medical outcomes (e.g., blood glucose levels, weight, waist circumference, blood pressure, etc.). The underlying biomedical expectation is that these tasks are prioritized and become a central focus in the patient’s life. However, patients with severe mental illnesses identified living with multiple priorities occurring at different points of time, forming and changing their practices around diabetes management. For many participants, diabetes management was regarded as a “chore”; an imposed task they had difficulty sustaining. For all participants in this study, their mental illness diagnosis preceded diabetes diagnosis. Therefore, their daily experiences of mental illness (e.g., symptoms, medication side effects, hospitalizations, etc.), and its related consequences (e.g.,
stigma, lack of housing options, poverty, fragmented services, unemployment, etc.) had significantly organized their existence by the time they were diagnosed with diabetes. Against this backdrop, diabetes management requirements were just “one more thing” (Participant 03, a 49-year-old woman of color with schizophrenia). For example, Participant 10 defined his challenges:

P: I’ve been taking my [psychiatric] medicine, [and] working this and that [refers to multiple responsibilities he has at his boarding home], and now it’s pre-diabetes, […] so it is hard to...manage both. It’s hard to do that. It’s hard! [makes frustrated hand gestures]

Participant 03 who lives in a boarding home, and is closely involved in a variety of community-based programs, stated:

P: It’s like a chore. Every morning you wake up, take it [diabetes medication]. Lunch time, take it before eating. Supper, take it before eating. And nighttime, take it before sleeping. You have to remember Humalog and Lantus [Humalog is an insulin, usually in an injectable form used for people with diabetes when oral medications are not enough to control blood sugar. Lantus® is also an injectable insulin, although from a different company]. [These are main things] you’re supposed to remember...

Therefore, in this project patients with severe mental illnesses identified their understanding of diabetes management as biological, physiological, and behavioral, in line with what has been reported in the literature (see for example, Brown et al., 1999, 2002; McCreadie et al., 1998; Thakore, et al., 2002), and aspects prioritized through psychoeducation as I observed during my fieldwork. Although, in addition to these understandings, patients also identified their experiences as formed through the contexts they were embedded in, and their decision-making behaviors as complex resultants molded through their past and present. Interview accounts, along with observations, demonstrate that patients’ decision-making behaviors expand beyond
personal will and are shaped by personal narratives, where these narratives are complex and diverse.

STOP TWO: Feelings and Emotions

The Canadian Diabetes Association position statement on diabetes (2008) states, “people with diabetes are often overwhelmed or frustrated by the burdensome demands of managing their chronic disease. They may feel angry, guilty, frightened, discouraged, depressed and unmotivated and their relationships may be strained” (p. S19). Therefore, it is further suggested that diabetes self-management education should incorporate strategies to prevent and/or manage psychological distress related to the diagnosis and management of diabetes (Conversational Map Manual, Section II: Living with Diabetes, 2008). The Conversation Map’s top upper section, “Feelings and Emotions” is designed to address these concerns, and to guide clinicians to explore patients’ feelings, reactions, and concerns following a diagnosis of diabetes. This is to “acknowledge and validate participants’ emotions,” which are believed to “affect choices you make in caring for your diabetes” (Conversational Map Manual, Section II: Living with Diabetes, 2008, p. 12).

Mapped Realities

According to the CDA clinical practice guidelines (2013), having diabetes and being engaged in numerous tasks associated with it may be stressful, and may result in a range of emotional reactions (Robinson, Luthra & Vallis, 2013). The upper top part of the Conversational Map presents a picture of a theatre-like building with a banner on top displaying the type, “Emotions and Feelings”, and pictures located on both sides and centrally. Four pictures on the left demonstrate “guilt,” “frustration,” “denial,” and “anger,” followed by one central picture
indicating “hope,” and continuing with three pictures on the right indicating “sadness,” “confusion,” and one poster on “relief and opportunity,” which appears just to be placed on a wall. In diabetes management, as is likely with other chronic conditions, when discussing how patients feel towards, and react to, a new diagnosis and the demands associated with it, emotional reactions and personal feelings tend to be understood as located within an individual. Within this understanding, the assumption is that emotional reactions are products within one’s psychological sphere, and therefore are direct products of it. From this perspective, feelings are then divided into negative, those potentially interfering with diabetes management, or positive, those that facilitate practices of diabetes management (Furler et al., 2008). This perspective is depicted, unproblematically, in the Conversational Map. Considerations of the ways in which these individual emotions are formed, and the role of the context in these formations, remain obscured.

Participants’ Experiences

While the Conversational Map’s exclusively portrays emotions and feelings as individually produced, in this study patients demonstrated that their emotional responses were also contextually and experientially constituted. Patients’ feelings towards diabetes management reflected their (1) personal living realities, and (2) previous experiences and interactions with the mental health system.

Living Realities

As previously mentioned, for patients in this study, the diagnosis of diabetes was secondary to their previous diagnosis of mental illness. Participants with severe mental illnesses linked their emotions and frustrations regarding diabetes management to the social contexts in which they
lived. Patients struggled to express their feelings regarding their circumstances, and they described needs that did not appear to be addressed through their clinical encounters.

For example, Participant 10 verbalized frustration and unhappiness in relation to his feelings towards the diagnosis and the way it affected his diabetes management:

P: You have to do exercises, they say, you have to exercise and ...eat properly, and don’t, eat junk food, junk food is no good for you [...]. If I have all these [new] things to worry about, you gonna eat more, you gonna become more depressed...the weight is the symptom...it’s not the cause [...]. It’s difficult, it’s a challenge, every day is...just not easy. Some days are ok; some days are not ok. Being tired all the time, getting up at eleven or twelve. You need to fight. If every day you have to wake up, every day you woke up and it’s always a fight, how would you feel? Every day you have to fight for this and that, and then you have to fight for your diabetes [...]. My girlfriend is always [telling me]: “why are you talking like [that?] [You] shouldn’t be so depressive.” But there is a reality: her life is hard, my life is hard, she lives in social housing, I live in [social] housing….If I am happy inside, I will be able to do this diet. But if I am always having hives about things what I don’t have and this and that, then…it’s gonna be harder to do that.

Similarly, Participant 07 (a 66-year-old white woman with schizophrenia) described diabetic side effects, specifically periodic incontinence, and which appeared to be a major point of tension between her and her medical providers. Her feelings of frustration, anger, and her eventual failures in compliance stemmed from her daily interactions with medical providers and her perceived inability to control disease side effects. These experiences formed a context where she felt threatened and controlled:

P: You cannot eat, [cannot] drink a lot of water [because] you urine all the time. You have to follow the diet they give you in the hospital, […] you have to eat what it is, what they gave you.
In this segment, this patient’s feelings of frustration developed in response to the medical regimen she felt was being forced upon her, rather than being emotional reactions towards the diagnosis of diabetes itself. Next, some participants regarded diabetes as a condition that could further deepen the social isolation they were already experiencing as a person with a severe mental illness. Participant 09, 58-year-old white man with schizophrenia, explained:

P: I need someone to talk to. I got a mental health to talk about. I won’t talk to them [medical staff] when they want. They have their own problems. […] I’ve seen other people who need someone to talk [but when they were not able to, they] become very angry, so I just control my anger, and sit there [talks about outpatient setting], and try to calm myself down. My psychologist, Dr. [name] told me on Saturday, “You’re smart enough to handle your own problems.” …You see, mentally ill are helpless and alone. They are alone. Everyone is giving up on them. They need someone to talk to.

Patients’ emotional responses varied in character and scope, with some reporting different emotional responses than those pictured in the Conversational Map. Participant 02, a 60-year-old woman of color with a long-standing history of bipolar disorder living in a boarding home, expressed a fatalistic approach to diabetes management:

P: What can you do? You have just to adjust to [diabetes]…I can’t live forever, so why we keep the hassle? I am just saying if you have less than a year to live, would you worry about saving money? You don’t know, you may walk down the street [and be killed], you don’t know about your destiny. So why worry about it?

From a clinical point of view, this patient may be considered noncompliant given her acceptance of an undesirable but seemingly inevitable poor outcome. However, her sense of disempowerment may be understood at least partially as a result of her living conditions and specifically those that give rise to a certain level of uncertainty. As expressed in her observation that “you may walk down the street … [and be killed]”), her response of “what can I do?” is consistent with her social and material circumstances.
Similarly, patients also identified that competing daily priorities played an important role in the formation of their emotional responses towards diabetes management. Some participants fully aligned themselves with diabetes management tasks, and therefore mirrored the Conversational Map presentations of hope, relief, and opportunities. Participant 01 commented, “[health providers] know I like a challenge […] to take care of myself.” In his case, his significant social isolation had forced him to prioritize self-management for lack of any assistance. Yet, his own reframing of his self-management steered his emotional responses towards that depicted in the Conversational Map under the “hope, relief, and opportunity” domain.

Others in contrast, such as Participant 09 (a 58-year-old white man with schizophrenia) who is living in a busy boarding home, when discussing how he takes medications, did not separate this experience from his housing difficulties (e.g., noise, waking up early, chaotic environment, all resulting in higher levels of stress). At this point it become apparent that his practices of diabetes management were part of his larger experience as a person living in a boarding home. In the boarding home, the hours at which he could take medications were constrained by the hours kept by others in the house:

I: At what time, do you usually test [blood sugar]?

P: Usually before right after I have Metamucil [is a bulk-producing laxative and fiber supplement, and at times prescribed for those with diabetes to lower cholesterol levels] or so, which is about…you, know, four o’clock [in the morning].

I: Oh, ok, that’s pretty early.

P: I don’t have any other choice! [Exclaims with gestures and raised voice]. Because if I [wake up] at five thirty at the morning, I go upstairs working, do my volunteer work, […] till ten o’clock. In the house, people can’t sleep. And these are very sick people in my house, can’t sleep, they are in pain.
In another example, participants linked their emotional reactions to other aspects of living as a psychiatric patient, as for example, taking psycho-pharmaceuticals with common side effect profiles such as dizziness, sleepiness, and lack of energy. Participant 03 linked her “not being happy” to medication use, and missing her diabetes management appointments:

P: I sleep very well actually, [clozapine] puts me to sleep at night [talks about clozapine, psychotropic medication used in people with psychosis, and potentially resulting in excessive drowsiness]. But, at the morning I feel sleepy […], I am not happy here. [When I take] pills [I] become groggy at the morning [and I need] to leave at seven o’clock [to make it to the diabetes appointment]. I felt very tired, so, I had to pass it till eight o’clock [and it was hard to follow daily routine].

Furthermore, participants also connected their emotional responses to their interactions with health care providers, pointing out difficulties and frustrations in negotiating their care. Participant 02 discussed the challenges with maintaining a prescribed diabetic medication regime. She became become visibly upset and described her attempts to negotiate medications and her care:

P: It’s really difficult [to talk about diabetes with care providers] because you have no sayings, no sayings…you know…I mean, no matter what you say it’s not gonna change it…what the sense? [expresses her frustration that her knowledge is often minimized, and not heard by health providers leaving her de-valuated]

In patients’ descriptions of their emotional responses to diabetes management, it became clear they emerged from their broader experiences of living as mentally ill persons. These experiences included, but were not limited to, personal realities of disempowerment, stigma, and overwhelm from multiple competing demands with limited support; all framing and forming particular emotional responses which infiltrated individual emotional responses towards diabetes and its management. In interviews, when we discussed medication regimes, patients shared their
struggles, difficulties, and frustrations, similar to those pictured on the Conversational Map. However, all these were formed by, and maintained within, the particularities of patients’ existence. The following quotes are illustrative:

People DON’T [strong emphasis, raised voice] understand that we also have emotions, and a lot of history behind me (Participant 09)

........

If I have all these things to worry about [he talks about his inability to sleep and waking up too early, hearing voices, having significant anxiety symptoms, present joint pain following a knee injury, living in a boarding home, etc], you gonna eat more, you gonna become more depressed… Oh my God… It’s other stuff… how the society see us, how they view us. Are we worthwhile? (Participant 10)

......

I can’t get my [diabetes] under control. You see, I just [feel] stressed out and [as a result] [blood] sugar can’t go down. (Participant 01)

Diabetes management activities are labor intensive, long-term, and demand motivation, skills, and mastery. These aspects have been shown to be challenging to achieve across populations, and to inevitably evoke strong emotional reactions in newly diagnosed persons (Robinson et al., 2013). Living as a mentally ill person may mean living under chaotic and stressful living circumstances, where diabetes becomes “one more thing” in a long line of deficiencies, which may have broader implications in understanding how emotional responses to diabetes are formed and sustained in people with severe mental illnesses.

Previous Experiences with Mental Health System

Patients also linked their emotional responses to their previous involvements with the mental health system. When discussing the importance of medical compliance, some participants
shared how their decision-making behaviors were informed by the threat of medical punishment. For example, Participant 04 was a 54-year-old single white man with schizophrenia who was currently living in the community, and previously had been involuntarily hospitalized in a high-security in-patient unit for treatment of acute psychosis. This experience formed a particular understanding of medical compliance and the repercussions of perceived noncompliance. He explained:

I: It sounds like you’re taking [diabetic] pills because...

P: [Health providers] tell me to! Yeah, if you don’t believe me… give me a couple of days [of not taking pills] and you’ll see I’ll be in handcuffs and shackles. [Health providers will] call police.

Similarly, Participant 01 also referenced involuntarily hospital admission following police involvement:

P: Like somebody may hit me and I hit them back…and I end up here [at the psychiatric facility]. I keep away from that…and they [he talks about what medical providers expect from him in relation to compliance] look for that *ex-pec-ta-tion* [very slow and drawn out emphasis]

Overall, participants overwhelmingly reported being treated as unreliable patients with a rather compromised level of capacity for self-care, which is of course true for some but not all people with psychiatric illnesses. Past involvement with criminal justice and mental health institutions formed aspects of their emotional responses in relation to their diabetes regimens, demonstrating a complex interplay of their past on their present health.

One particularly powerful interview, that with Participant 03, a 49-year-old woman of colour with schizophrenia, helped me to understand how some patients were not metaphorically advancing on the Conversation Map. Like many others, this woman identified themes such as
“not [being] heard,” or “dismissed,” as she was “not [taken] seriously” in her attempts to negotiate support for her care with medical providers. “It made me angry. It’s MY [exclamation and strong emphasis] life!” she told me, demonstrating her feelings of frustration in relation to diabetes management. Indeed, her experiences sensitized my awareness and helped me to see patterns echoed through my fieldwork. What emerged were multiple observed instances of dismissal by medical providers when requests for support by patients departed from the overall theme of the clinical encounter. The following clinical group observation is one such example:

10:05 am. The nurse comes in, and the pharmacist follows. The nurse starts off by asking every patient about their interests and hobbies. Then she advises them to bring their art work, if they have one, next time. She introduces the topic of diabetes and explains the procedure: e.g., this group will meet once per 3 months, “we will discuss diabetes and what we need to do,” the meeting place, and reminders about appointments. She also encourages patients to attend regularly. She then moves to the explanation for today’s session by briefly explaining that she will talk about what diabetes is, and how it affects patients. She also introduces the pharmacist and tells patients that he brought a glucometer to demonstrate for them.

A female patient interrupts her by saying what she knows about diabetes. She mostly refers to her difficulties in diet and her limited choices as her boarding home is not able to accommodate her nutritional needs. She then begins to discuss the lack of money in her ODSP cheque. The nurse nods, and then responds with “Let’s park it,” and continues on with the standardized group agenda from the Conversational Map manual. […] Throughout the remaining session, the patients remain quiet with no additional questions and no interruptions. The nurse explains how diabetes is a disease of the pancreas, and reminds patients that they should be mindful of their blood sugar levels. When the group is completed, the nurse asks the patient who talked at the beginning, what she thinks. Patient replies hesitantly, “I think it’s okay.” The nurse thanks everyone, and patients are dismissed.
What I took away from such encounters is that participants’ emotional reactions to diabetes management are not solely individually driven, but are shaped by their social and historical locations in the health system. A key empirical finding is the obscuring of the patient’s concerns in structured clinical encounters. As a result, many participants reported negative emotions that were provoked within interpersonal clinic relations. In diabetic clinical practice, patients’ negative responses are to be recognized, and then corrected, by medical providers, so that a patient may move towards a more positive and productive state (Conversational Map manual, 2008). While the ideals of the Conversational Map included the acknowledgement and validation of participants’ emotions, this was not what I observed. Patients in this study also indicated during their interviews that their emotional responses were frequently discounted by care providers. As negative emotions are believed to inhibit progress, it is clear that the person experiencing distress cannot move forward. My empirical data suggest that emotions influence individuals’ knowledge around diabetes and its management, and that diabetes management is as much a social and emotional as a technical task.

STOP THREE: Complications of Diabetes

Public health interventions in diabetes emphasize the need to prevent, or at least to minimize the negative consequences of diabetes, such as physiological changes in heart, kidneys, and nerves. Diabetes complications are costly for individuals and the public, both directly and indirectly, as they are the major causes of blindness, end-stage renal disease, non-traumatic amputations, and cardiovascular disease in Canadian adults, which may significantly impact the life of individuals, their ability to function and overall quality of living (Canadian Diabetes Association Clinical Practice Guidelines, 2013). These significant adversities are often explained by substantial changes in organ physiology that results in physical suffering, and therefore diabetes
Complications become understood from the position of physiological dysfunction, associated bodily limitations, and increased dependency on others which increases health costs. These reasons are often assumed as the main rationale for the promotion of diabetes self-management through compliance.

**Mapped Realities**

On the Conversational Map, “Complications of Diabetes” occupies a small space at the upper top between “Feelings and Emotions” and “Signs of High/Low Blood Glucose Levels.” It is visualized as a sculptured fountain with a female archer in a shooting position, effortlessly balancing on a ball on one leg. Water spouts from the sculpture into the fountain. Located around it are words, such as ‘brain,’ ‘eyes,’ ‘heart,’ ‘kidneys,’ ‘sexual health,’ ‘feet,’ and ‘nerves,’ which links cardiovascular and neurological damage to long-term changes from diabetes. The symbol of balancing on a ball is an accurate illustration of diabetes management practices, as it suggests the numerous difficulties one may face when dealing with the prevention of diabetes complications. On the other hand, the forward posture of the archer with a bow and an arrow ready to shoot signals dedication, skill, and readiness to accept this challenge.

The potential devastating effects of diabetes complications makes prevention a major focus of clinical practices and regulatory policies. During my on-site fieldwork, and when interviewing health providers and administrators, I found that the prevention of complications is an implicit framework guiding clinical practices and administrative decisions. Its importance is re-emphasized through several administrative means. Health care providers are mandated to report information on diabetes’ physiological indicators at regular time intervals to the Ontario Ministry of Health and Long Term Care. This is achieved through the use of a specific
computerized form, namely the Diabetes Flow Chart (see Appendix XIV: Diabetes Flow Chart), which is embedded into an electronic medical record (eMR), which is a major computerized document at the FHT that collects patient-relevant information. Accurate filling out of the eMR, and therefore diabetes flow charts, for each patient is a mandated part of routine clinical practices in the health setting.

I recorded a typical medical assessment preceding the educational group as follows:

09:05-09:30 a.m. Medical Exam

The nurse, who is a white woman, checks her computer to locate the patient’s name in her chart, which are lined up in particular time slots. She checks the patient’s first and last name, and walks into a waiting area, calling the patient’s name, and saying hello. The patient is a tall man of color, of stocky build, who wears several layers of clothing. The nurse shows him the way to the exam room, offers him a chair, and sits on the table where the computer is, halfway facing the patient. She opens the patient’s file on the computer; simultaneously chatting to the patient and asking how he is doing, how are things doing, and what is new with him. The patient responds politely to all questions, but does not elaborate much on his answers. Meanwhile, the nurse opens the ‘medical’ tab in her computer chart with a series of questions located on the left and empty boxes located on the right.

[Chart. Includes the patient’s name on the top left, followed by the patient’s date of birth. There is a big icon right below with the family physician information on it, followed by a grid with the patient’s lab values (complete blood count, liver and kidney indicators, etc.), blood pressure, heart rate, weight, height, history of coronary or kidney diseases, eye and foot exam results, influenza/pneumonia vaccination status, and smoking and alcohol use. There are three questions at the end on ‘patients,’ ‘goals,’ ‘barriers,’ and ‘motivation.’ [I have realized that these questions are posed at the conclusion of each diabetes group meeting, answered with the help (and directed guidance) of professionals]. There are also tabs on ‘social factors,’ ‘history,’ and ‘risk factors’ on the patient chart, but the nurse does not use them during the exam].
She starts asking the patient each of the questions in the series, such as his symptoms, whether it is hard for him to breathe, how many cigarettes he smokes, and how much alcohol he consumes. She checks his answers on the right portion of the form, corresponding to left-side boxes. She leaves some boxes blank, and fills them in afterwards when she measures his blood pressure, weight, height, and waist circumference. She then asks about his eating habits, reminding him that he needs to be mindful about his sugar consumption. He nods, and explains he has cut down on cookies. She continues with preparation for the blood test draw, places a prepped tray on the table, and explains to the patient, “We will do blood work, then urine sample, then you will have a breakfast, and we will have diabetes group.” The patient sighs, but rolls up his sleeve. The first needle poke seems to be painful, the nurse apologizes, and the patient tells her this is likely because he just had another blood test done a couple of days ago. He grimaces, and the second poke is successful, and the nurse draws the blood in three blood test tubes, labels them, and places them in the tray. She asks him to lay down on a stretcher so that she can perform a foot exam. She asks a standard set of questions, such as whether he experiences numbness, tingling, or cracks, and whom does his foot care. She checks the appropriate boxes on the right of the form, depending on his answers. The patient has some cracks on his feet, and the nurse advises him to use some lotion to prevent infection. She tells him the visit is completed, and he asks permission to go for a smoke [cigarette]. The nurse responds that he can go for a smoke, but reminds him that he needs to be back for breakfast and attend the educational group.

In patient-provider interactions, when medical information is conveyed to the patients, the discussion around the negative consequences of diabetes is facilitated from the biomedical viewpoint. A field note taken during a metabolic group, focusing on foot care as a way of preventing diabetic neuropathy, was recorded as:

9:40 a.m. The group starts. Two patients I have interviewed before (both are women), and another patient (man) are present. Today’s topic is “Foot Care.” The Conversational Map (the one dedicated to foot care) is placed on the table with patients seated on one side, and nurse (and me) seated across. Another staff member is serving food (small bowls of oatmeal, bagels with cream cheese, bananas, and glasses of water with lemon) before the group starts. A patient asks how many more sessions are left, and it appears
that only one more session will be held, and then the group has to decide on further directions.

9:45 a.m. The conversation starts with an introduction, brief reminder of previous topics, and patients stating their names. A nurse leads the conversation. She asks each patient about their previous goals and how successful they were in achieving them. She praises each one of them for achieving their goals. One of the patients I interviewed previously mentions her weight loss, another patient report cutting down on cookies, followed by the last patient stating that she has stopped eating “pizza and starch.” The nurse listens to all of them and praises them, then moves to the next topic of foot care, pointing to the Conversational Map on a table.

9:54- Nurse uses the Conversational Map as a guide, pointing out to different places (e.g., checking your feet, proper footwear, hygiene, and appointments). She points out and talks about potential complications, then advises patients on what they may do to improve foot care. She uses ‘flash cards’ from the Conversational Map education kit to demonstrate the potential ‘dangers’ of poor foot care, and then continues with the conversation on how to check feet properly and what to use.

The discussion moves to footwear, e.g., what socks patients are, or should be, wearing. The nurse points out footwear on the Conversational Map, and then talks about the necessity of buying cotton socks as they absorb moisture the best. Immediate questions from patients concern the price of cotton socks. At this point patients seem more engaged, and listen to the nurse’s answers. The nurse talks about “different possibilities,” and tells the group not to purchase the kinds of socks Dollarama is selling, and if patients do not know what kind of material the socks are made from, she encourages them to ask a customer service representative. [Memo: judgment is made from standpoint of the nurse, who has access to information]. At this point, all the patients nod, and the discussion turns to moisturizing, e.g., the types of lotions and their prices.

As demonstrated above, disease complications, as visualized in the Conversational Map, continue to be framed and taught within their biomedical terms of physiological dysfunction,
resulting in potential functional limitations, and without regard for the patient’s economic limitations, as will be addressed in more detail in the next section.

Participants’ Experiences

In extending the above ideas, participants in this study identified other components of diabetes management that magnified their sense of social deprivation. Specifically, participants anticipated that diabetes complications would worsen problems such as social isolation, aging, and limited financial resources. For example, Participant 01 described complications of diabetes that extended beyond medical or bodily dysfunction (e.g., bodily suffering). He described how diabetes might result in the exacerbation of his social struggles (e.g., having no family or additional financial support):

P: [Before] I was just taking a pill. [Now] I take it very serious[ly]. I know I am getting older, and I have nobody, I have no family if I get sick to visit me. [That’s why I] take it more serious. I can lose my fingers, I can lose my eye, I can lose some part of me. I don’t want to. I have nobody around me. You don’t want [to rely on a person] you don’t know [talks about personal support workers]. You don’t [want to ask], “can you do it for me?” [Personal support workers] don’t show [up], [they] don’t come. You don’t have anybody to come and say, “Do this for me, do that for me.”

Participant 01 was aware of diabetic complications from the physiological perspective, such as “can lose my fingers.” However, it was social aspects, such as lack of support and social isolation, that framed his understanding, and informed his further actions. Similarly, Participant 02 expressed an understanding that self-care could improve his quality of life. However, his predominant concern with aging as a diabetic was with social isolation:

P: You gonna really pay attention to [diabetes] to learn more…to live healthier. But, I don’t know… you probably see people in their walkers, they are on insulin, and they
have [diabetes] permanent. […] Are you gonna live like that? […] I mean, what’s the greatest thing for you [if following all prescribed diabetes management tasks?], lonely to live, you suffer.

These quotes demonstrate a common finding in this study. On one hand, very much in line with common clinical understanding, and echoing public health policies, participants demonstrated a sound knowledge about and understanding of the potential physiological complications of diabetes. On the other hand, their understandings of diabetes complications were also contextually bounded, and reflected concerns about suffering and social isolation; these important aspects remained unaddressed in the Conversational Map.

STOP FOUR: Recognizing and Managing Symptoms

Optimal blood glucose control is fundamental to the management of diabetes, as low blood glucose levels (hypoglycemia) may result in coma, convulsions, and encephalopathy, and high glucose levels (hyperglycemia) are associated with diabetic ketoacidosis, loss of consciousness, a stroke-like state, and cognitive impairment (Berard, Blumer, Houlden, Miller & Woo, 2013; Hultsjo & Hjelm, 2012). Therefore, facilitating the patient’s ability to recognize the signs of altered blood glucose levels is a central goal in diabetes health teaching.

Mapped Realities

The theme of recognizing and managing diabetes symptoms associated with blood glucose levels on the Conversational Map is divided into two categories: (1) understanding the signs of low and high blood glucose levels; and (2) ways of measuring them. In the Conversational Map, ways of blood glucose monitoring are visualized through the use of the glucometer and blood tests to collect levels of glycated hemoglobin (A1C). A1C refers to glycated hemoglobin that is a protein, which appears in the blood stream and is used as an indication of blood glucose over a
particular period of time (Berard et al., 2013). A1C is collected by clinicians at regular time intervals, usually quarterly. It serves as an objective measure to judge the effectiveness of a particular diabetes treatment in a particular patient population, and is reported to regulatory authorities by the means of annual reports with statistical indicators. A1C is clinically and administratively significant. While having no immediate impact on patients’ experiences, it becomes significant in relation to patients’ attendance to the clinic, where patients’ service delivery becomes structured around the necessity to collect this indicator over particular periods of time. In my interviews and observations, the importance of A1C collection was not questioned by any respondents, and the clinical focus remained on the testing of A1C.

The Conversational Map depicts “Signs of high blood sugar” at the upper left corner as stairs to the restaurant along with the terms ‘thirst,’ ‘frequent urination,’ ‘difficulty concentrating,’ ‘fatigue,’ and ‘blurred vision.’ Next, the “Signs of low blood sugar level” image is positioned at the exit from the restaurant moving further down the road, and includes signs such as ‘trembling,’ ‘headaches,’ ‘sweating,’ ‘anxiety,’ ‘hunger,’ ‘fatigue,’ ‘nausea,’ and ‘confusion.’ The upper right quadrant presents a picture of a person’s hands on a table in the process of getting a blood drop for a glucometer reading. The glucometer is visible on the table with patient poking his/her finger. The importance of blood glucose monitoring is reinforced through positioning it at several places on the Conversational Map, which supports the discussion on blood glucose monitoring on different occasions. For example, “A1C and Blood Glucose Levels,” which is positioned centrally and at the very beginning of the road, depicts a man facing the board with a compass as a navigation device. This positioning encourages clinicians to address blood glucose monitoring during the early stages, when the discussion on diabetes understanding as a physiological illness occurs. Pictures of blood glucose levels and the glucometer are also located between ‘diabetes consequences’ and lifestyle changes, which
facilitates further exploration of monitoring as they mark both the beginning and the end of each section.

Therefore, the medical understanding of recognizing and managing symptoms of diabetes is twofold. First, it includes actual knowledge about symptoms as a way of knowing about and hence preventing or at least minimizing these symptoms. Secondly, this understanding implies that this knowledge should be verified through specific objective means, such as the patient’s use of a glucometer, or as the laboratory test for the A1C indicators.

Participants’ Experiences

In this research study, participants with severe mental illnesses experienced challenges with distinguishing symptoms related to blood glucose levels from those they experienced as a result of their mental illness and/or their use of associated psycho-pharmacological agents. The vast majority of participants relied on the use of a glucometer as a starting point to trigger further actions in relation to diabetes management, while others relied on their own understandings as to when particular diabetes management actions should be employed.

“Being tired all the time”

Findings suggest that at times patients’ experiences of physical symptoms, such as fatigue, tiredness, nausea, hunger, anxiety, and difficulties in concentrating, were difficult to distinguish from those previously known to them in relation to their psychiatric conditions. Patients with severe mental illnesses in this study routinely identified symptoms of tiredness, significant fatigue, hunger, and difficulties in concentration as consistently present, where these experiences were not directly linked to or explained by changes in one’s blood sugar level.

Participant 10 commented:
Some days are okay; some days are not okay. Some days...they took me off one of [psychiatric medications] cuz I was getting better. Being tired all the time, getting up at eleven or twelve. You know, I try to take [medication] early but I ended up getting up late. […] It’s medicine, so it’s really hard. I don’t wish it on anybody. Some days you’re happy, some days you’re sad, sometimes you feel...out of it. It affects your daily relationships and stuff, and […] expectations of people.

In people with severe mental illnesses, symptom recognition may be altered or transformed by their experiences related to their psychiatric illness or/and psycho-pharmaceutic side effects, and their present mental health state. Yet the mechanisms of any interference with symptom recognition by the patient remains unaddressed in the logic of the Conversational Map. Instead, assumptions persist of patients’ unproblematic reception and interpretation of troubling findings by diagnostic instruments, such as the glucometer and routine blood tests, in terms of symptom recognition and resolution.

**Self-Monitoring of Blood Glucose: Glucometer**

The use of an instrumental device, the glucometer, to approximate blood glucose levels in individuals is highly encouraged by health care providers as a simple and accessible way of blood glucose levels monitoring. Blood glucose monitoring continues to be viewed as having individual (e.g., prevention of a medical crisis and enhancing individual well-being), clinical (e.g., preventing medical complications), and administrative (e.g., decreasing medical emergencies and service utilization) benefits (Clinical Practice Guidelines, 2013). The use of glucometers is also supported on a regulatory level with partial financial coverage for the device itself, as well as specific number of blood glucose test strips for those eligible under the Ontario Drug Benefit Program, Ministry of Health and Long-Term Care (2015). This is despite recent debates in relation to the accuracy of readings through glucometers, with studies demonstrating that more than half of the testers fail to produce accurate readings (Hasslancher, Kulozik &
Platten, 2013), and reading deviations may be as high as ±20% (Mann et al., 2007). The message behind glucometer use, confirmed in my observations during fieldwork, continues to be that it is easy to use, and is an easily accessible and reliable way of monitoring one’s blood glucose.

Understanding Self-Management of Blood Glucose Levels: Personal Labor

For patients in this study, the monitoring of blood glucose levels using a glucometer was neither straightforward nor easily accessible. Blood glucose self-management required patients’ mental and physical investment in several domains. Specifically, (1) knowledge in the physical act of using a glucometer; (2) ability to allocate time and resources to ensure specific time slots are available throughout their days to perform activities of self-management; and (3) knowledge and skills to maintain the device in working condition, which also included replacements. Participant 01 described in detail the step-by-step actions he performs to monitor his blood glucose using a glucometer:

P: [Every] morning, I wake up at 8 am, I go to the washroom, I eat, wash my face, clean up, and I test my sugar. […] and then I take my pills [refers to both psychiatric and diabetic]. I eat lunch, test [glucose]. If [glucose is] normal, I don’t have to take any pill, I have to take nothing.

I: [How often should you] test?

P: [interrupts] Three times per day. [I take] two [pills] at the evening for the bedtime. One [pill] is [at] four o’clock, and I am going to eat dinner. And at bedtime I test [glucose] again and see what the marks [he talks about number on glucometer], so I don’t give myself [too much insulin]. I also give myself two units [of insulin] at night [if I have glucometer readings of] eight and nine. [And if I have high readings] I take
sixteen [units of insulin]. In the morning when I [wake up], then [glucometer reading will be] under 4.7, 4.8, 4.9.

I: When you measure your blood sugar, how do you actually do it?

P: I use a strip, put it in the glucometer, and [poke] a finger [with a needle], squeeze it [talks about obtaining a drop of blood, and physically demonstrates on his finger how he does it], put it on [a strip] and [glucometer] will [show how] much it’ll be. [Before I test], I am at the kitchen, preparing meal. [I start testing while] water [boils] for a tea, and I poke [demonstrates how he needle pokes his finger]. I eat after I do the testing. And I have my tea and I have my breakfast, and I’m set to go. [If on this day] I [need to] go to see a doctor, I need to tell him [about glucometer readings].

This account provides a clear example of what is involved in the practices of self-management of blood glucose levels through glucometer use. It is apparent that the seemingly simple task of blood glucose monitoring must be managed within the reality of other domains, where self-management requires patients’ awareness and dedication, as well as the knowledge and ability to recognize the significance of fluctuations in blood glucose levels. It encompasses significant emotional and cognitive work, often to the point of mental preoccupation with monitoring, as the patient needs to constantly assess and reassess their physical and mental state, and remember and perform each of the required steps. These numerous, time-consuming, and complex tasks signal the physical, mental, and emotional labor required, which are performed alongside other domains of lifestyle functioning.

Self-Management of Blood Glucose Levels: ‘Free but not Free’

The provincial government of Ontario has recognized the importance of blood glucose monitoring through the provision of financially subsidized access to glucometers by those diagnosed with diabetes through the Ontario Drug Benefit plan, where glucometers are made available at no charge through pharmacies.
Participants in this study, however, drew attention to the existence of hidden costs, which are not readily apparent, but heavily influenced whether they were able to consistently use the blood glucose monitoring tool. For example, Participant 09, a 53-year-old white man with bipolar disorder, explained that he decreased the frequency of his blood glucose checking due to financial constraints. He described hidden costs, such as the purchase of new needles, batteries, strips, and eventually a new glucometer (after the first one wore out). He referred to blood glucose monitoring as “free but not free.” He explained:

P: The glucometers are free. It’s the strips that cost. […] I need one or two a day […], a box of strips costs about forty dollars. The meter is free, and the lancets are free, but the strips cost money. […] I am already through three bottles of strips. […] I have to pay for the strips...and you buy lancets, which cost 10 dollars a box, that’s all. So, it used to come with the meter. That’s why it costs that much. They say it’s free...but it is not free.

I: Why don’t you measure blood glucose every other day?

P: I can’t afford the strips. […] Two hundred [dollars] a year, I can’t afford it, it’s seventy-two dollars for a package, I can’t afford it. I am on ODSP [Ontario disability support program]. Two packages a hundred [dollars] all together. [I] pretty much know what I eat and I have to take. If I worry-I test it again.

This theme of hidden costs was consistent across most patients’ interviews. As this excerpt demonstrates, blood glucose monitoring costs add up, and may become significant. An individual’s self-management of blood glucose levels through the use of the glucometer exists in relation to their life context. Financial hardship resulting from limited governmental assistance may restrict the degree to which an individual can comply with medical guidance. Patients’ interviews also suggest that they had to weigh risks and benefits by assessing what resources are available and the best ways of using them. Patients positioned themselves as knowledgeable and
capable, an understanding often overlooked in medical practices, as patients with mental illnesses continued to be viewed as having limited understanding or compromised capacity.

**Blood Glucose Monitoring through A1C: Mandated Attendance**

Despite the complex considerations and work involved around self-management of blood glucose levels with the use of glucometer, it continues to be perceived as a useful adjunction to other measures, primarily to the collection of glycated hemoglobin levels. Its collection remains a preferred standard for assessing diabetes control, and should be measured every 3 months when glycemic targets are not being met (Berard et al., 2013). During this project, I observed educational groups over a 3-month period, and clinical meetings that focused on the topics of patient attendance and retention, including increasing the regular attendance of people with mental illnesses and diabetes. At both these groups and meetings, the collection of glycated hemoglobin was considered a primary component of the medical visit. To achieve these objectives, I identified that health care providers made significant alterations in their practices, including having nurses work to their full scope of practice, such as venipuncture and contacting patients ahead of time to facilitate attendance. Practice alterations also included changes in health care setting operations, such as budget allocation to ensure breakfast would be provided, providing coverage for nurses on days when they undertake clinical duties at the metabolic clinics, assigning and funding separate nursing hours for patient follow-ups, and having senior administrators liaise with other medical professionals to ensure patients regularly attend the clinic. As my project progressed, and I gained access to the secondary data sources, specifically electronic records, and the health setting’s annual reports, I found that consistent patient attendance attained crucial importance for both clinical (e.g., A1C collection to support diabetes monitoring and prevention of complications), and organizational (e.g., annual reports,
accountability to the governmental bodies, and physician billing) reasons. Indeed, at one point during my fieldwork, the diabetes care program was perceived to be in jeopardy given that the consistent participation rates of diabetic patients with mental illnesses had fallen. This triggered a series of administrative and clinical actions to ensure and enhance consistent attendance, as my observation of a clinical meeting revealed:

*Discussion on “Keeping clients.”* Senior administrator raised concerns that given a [time delay] gap between the medical visit and an educational module, some patients leave premises prematurely and do not wait for the group. A question was posed to the group, “how to keep clients occupied while waiting for Diabetes Education group?” Because the clinic usually has up to eight patients, medical personnel try to process them quickly, and management had earlier assigned an extra nurse to speed up the process. A nurse responded that despite their attempts to ‘maintain the flow’, some patients come early, and then have to wait until a nurse is free, which in some instances may result in patient frustration and a higher level of stress, since patients are asked to wait for a diabetic group, as nurses are still busy working with other patients. “Keeping them” until the educational part seems to be very important: (1) it was suggested that ‘breakfast’ keeps them occupied (confirms my point from previous notes); (2) having an eye doctor was also discussed as an option for ‘entertainment’ (for triaging, etc.), but then was dismissed due to the high complexity of setting this up; (3) nurses were seen as key individuals to ensure patients would not leave (for the last group, a nurse was physically present during the ‘breakfast’ period and talk to everyone to make sure patients are ‘engaged’ and ‘not leaving’). Although it seems challenging, as in this case one nurse has to sit and there is less help to the remaining two nurses to ‘process’ patients. Solutions discussed: (1) not using the waiting room at all, (2) providing educational video for patients while waiting for the group.

The abovementioned example demonstrates the contradictory and complex nature of clinical practices in health setting in relation to diabetes care to those diagnosed with mental illnesses. On the one side, regular attendance is, of course, important to the patient, as it allows regular monitoring and therefore, early prevention of complications in case they occur. It is also clear
that both clinicians and administration engage in creative and complex strategies to ensure consistent care is available to this population. However, what remains problematic is that administration remains under the pressure of reporting to demonstrate accountability, mandating setting to put in place a system, which does not necessarily fit the needs of population it is supposed to help.

Participants viewed mandatory attendance quite differently than did diabetes clinic staff. Participants related attendance difficulties that were associated with multi-morbidity, as well as with low social support. For example, Participant 03 had multiple health care providers, including a psychiatrist, nurse, endocrinologist, family physician, and diabetes care team. She contrasted her challenges with mandatory appointments against those of a cancer patient who enjoyed strong familial support:

P: Mr. [name], an artist... he taught at [name of university] about two to four years ago. He... is dying of cancer. And [his relatives] are taking him everywhere. His girlfriend, she is driving him everywhere: doctors’ appointments, and chemo.... And I said, ... “I can’t make it [to the appointments]”. I know I am sick.... I have schizoaffective disorder.... When you sick you have a lot of appointments...very busy, a lot of things to go to.

Therefore, her diabetes management experiences in terms of failure to fully comply with mandatory attendance were shaped and constrained by her underlying life context, specifically numerous competing medical demands, and secondly, having fewer social resources to assist.

STOP FIVE: Medications & Lifestyle Behaviors

In diabetes management, best practice clinical care compliance is defined as the appropriate use of pharmacological agents, making appropriate dietary choices, and engaging in regular physical
activities. On the Conversational Map, these concepts are represented by three sections, which occupy roughly two-thirds of the map. The first section is ‘Healthy Eating,’ which depicts a man and a woman of color sitting at a picnic table, with several plates of vegetables and fruits in front of them, with the woman pouring a glass of water and giving it to the man. The second section is ‘Keeping Active,’ which combines a set of smaller pictures, specifically a white woman walking with weights, another white woman walking her dog, and two white individuals, a man at the front and a woman behind him, riding a tandem bicycle, with wheels named ‘taking medication,’ ‘keeping active,’ and ‘healthy eating.’ The third section, ‘Taking Medication,’ depicts a white woman on the upper floor of the house, taking her medications from the cabinet, with three other people leaving the house and moving towards a car, and with a man in a baseball hat raking fallen leaves. These images present the message that diabetes management is contained within the three domains of drugs, diet, and exercise, and further that individual compliance with domain activities is easily managed as indicated by the smiling, able and engaged stance of the depicted characters. The Conversational Map’s conveyed message is that successful management of diabetes is one of self-management performed through domain compliance. This message is also strongly conveyed in clinical practice, as observed throughout the duration of this project.

Compliance is a broad term that includes but is not limited to several domains, such as taking medications (e.g., psychiatric and diabetic) and following lifestyle recommendations. For people with severe mental illnesses, compliance is viewed as improving functioning and it is often equated with effective clinical care (Fawcett, 1995; Salzman, 1995). Following providers’ recommendations in relation to diabetes is important, because research links lack of patient compliance to higher levels of diabetes medical complications (Chiverton et al., 2007; Fulton et al., 2001) and higher societal costs (Breton et al., 2013). However, severe mental illnesses are
often associated with a particular level of individual impairment, which is often cited as one potential explanation for poor medication compliance in this population (Velligan et al., 2009).

Discussions regarding patient self-management by compliance with medications and lifestyle behaviors were identified as important during my observations of patient-provider interactions. In order to facilitate conversation about patients’ behaviors and their decision-making processes, each educational group concluded with a review of specific goals on diabetes management as depicted in ‘My Goals Card’ (see Appendix XVI: My Goals Card). Patients were expected to report on medication, diet, and exercise goals, and their progress and success was regularly reviewed. This information was then immediately collected by health providers, and later reported to the governmental bodies as a part of accountability practices, which further define FHT programming and cost allocation on annual basis. Thus, the collection of this information was arguably serving the clinicians’ rather than the patients’ interests. The following two field notes illustrate the response by providers to the compliance information offered by patients during meetings:

Note 1

The nurse continues describing setting ‘goals’. She describes what each patient is supposed to be doing, and asks them to indicate what barriers would be to achieving these goals, and then to specify their level of motivation. The nurse talks to each patient emphasizing the benefits of exercising, such as “it’s good for your diabetes.” Patients share the variety of activities they do (e.g., biking, walking, playing some sports). It appears that the vast majority of patients walk a lot due to the limited number of public transportation tokens they are provided. Another nurse confirms that he gives one token to his client X, so X must walk to the outpatient clinic, but is afterwards able to take public transportation to return home.
Patient Y, who looks like a middle-aged Asian man, talks a lot about how he likes different types of sports, such as tennis, basketball, and surfing. He also states he plays sports, and basketball in particular, in his neighborhood when other people are around. Patient Y was almost mute with no eye contact during this group, but became surprisingly engaged and chatty when talking about his interest in sports. The nurse tries to redirect him and move onto the ‘goal setting’ trying to fit his interest in sports into the ‘goals’ on a card. The nurse also suggests patient can use hospital swimming pool, but Patient Y refuses, and tells the nurse he does not like swimming indoors. Then the nurse suggests basketball on weekends, but the patient responds that he plays only when somebody else is around. The nurse asks, “So, what would we do?” The patient agrees on tennis as his potential goal. [Memo: I later learned that Patient Y’s neighborhood is widely perceived as unsafe, and he does not feel comfortable spending time outside on his own, which may explain why he only plays sports when other people are around].

Note 2

11:20. The nurse moves into ‘goal setting.’ She fills out a small card for everyone after asking about goals, motivation, and barriers to achieve this goal (note: all these questions are in a computer file).

Participant 01 lists his goal as ‘having fish four times per week,’ and rates his confidence in achieving this goal as being ‘high’ [the nurse had asked patients to rate their motivation on a scale from “not confident and no motivation” to “high motivation, very confident.” Asking patients to rate their motivation is a commonly used health behavior intervention tool to help clinicians to assess barriers and help to address them]. He is praised for his goal and motivation.

There is a major emphasis in clinical practices, and regulatory policies, on the promotion of diabetes self-management through compliance with pharmaceutical and lifestyle behavior recommendations, which are understood as the best way of treating and preventing diabetes. However, this understanding continues to assume a linear understanding of compliance, where no underlying social inequities exist among patients, and therefore individual context is
perceived as largely irrelevant to one’s ability to self-manage. However, this assumption was overwhelmingly challenged in patient accounts in this project.

Taking Medications

Mapped Realities

On the Conversational Map, ‘taking medications’ is pictorially displayed between the entrance and the exit. There, a white woman removes a bottle of prescription medication from a medicine cabinet located above the sink in her detached family home’s bathroom. In so doing, the taking of diabetes medication is thereby depicted as a simple, solitary act. The particular components of the act, and the processes which support it, are obscured. Specifically, the physical process of medication taking (e.g., the multiple actions of medication storage and dispensing, and its ingestion and effects, etc.); associated work (e.g., decisions, meaning, experience, etc.); and connections to the social and physical environment (e.g., how, why and by whom medications are prescribed; space and place of physical storage along with its accessibility and availability, etc.), remain unaddressed. Therefore, an individual is pictured as being fully in control of all decisions regarding her health, in this case in relation to taking medications. This understanding continues to build an assumption that medications are readily and unproblematically accessible, properly stored, and conveniently and accessed when one decides to do so. The Conversational Map showcases an individual as living in his/her private dwelling, which assumes some level of privacy is available, as well as that this individual has the resources to obtain, store, and access medications. In addition, the character appears to be physically and mentally able to perform a physical act of medication taking. The underpinning complex considerations of financial and housing arrangements, physical and mental capabilities, and ability to allocate time and
resources to engage in the act of medication taking do not appear to be a part of the diabetes conversation and do not appear on the Conversational Map.

Participants’ Experiences

Individuals with severe mental illnesses described medication taking as a complex, relational and contentious process, in contrast to the unproblematic act depicted in the Conversational Map. Participants indicated their decision-making behaviors around medication compliance were informed by their living situations, and in particular, by regulations imposed by others.

Living as a Person with Severe Mental Illness

First, participants with severe mental illnesses linked their experiences of medication taking to their previous interactions with the psychiatric care system. In these previous interactions, patients reported challenging experiences when their behaviors around medications were not aligned with expectations of health care providers. Participant 04, a 54-year-old white man with schizophrenia, identified difficulties with lifestyle changes in his diabetes management, but continued to comply with medications prescribed, when I queried his choices to prioritize one action over others:

P: [I am on] clozapine. And I forgot to take one... two pills... I am supposed to take, [Clinician name] got sooo angry with me. She said, “You have to take it. The reason why you’re supposed to take it on these days is that... Otherwise you may come to hospital again.” I say, “No, wait!” [Exclamation, raised voice, and then laughing rather awkwardly]

Some patients noted that their overall lack of control over their decisions, including those in relation to medications, left little room for negotiation around pharmaceuticals. An illustrative
example includes the treatment negotiation experiences of Participant 03, a 49-year old woman of color with schizophrenia who lives in a boarding home:

P: [Clinicians] have no idea what they are talking about. It is my life! [exclamation, very strong emphasis.] they are dealing with, not their life, MY life. [exclamation, and animated gesturing]. [Clinicians] sit next to each other and looked at me saying, “you need sugar.” I was 9.7, I shouldn’t go anywhere four to seven. They sit and [tell me] “okay, we are telling you: there is no room for arguing.” [Exclamation, strong frustration]. They would not listen to me […] It is most aggravating, because I am telling them, “I cannot take sugar.” So, they are not happy with me, and I am not happy with them.

This excerpt is a part of a larger discussion with Participant 03 concerning her decision-making around different aspects of diabetes management. She described a preexisting lack of communication between her and her medical providers, which had created a feeling of general mistrust that permeated other areas of her life. Her diabetes management decisions appeared to be built on this underlying context of mistrust. However, in the Conversational Map, preexisting tensions with health care providers such as these, and the potential implications for diabetes self-management, were missing.

Next, the standard treatment for severe mental illness often requires that patients take numerous medications. Concerns around polypharmacy and its detrimental effects on personal wellbeing, have been recently acknowledged (Megna et al., 2007). In this research study, the overwhelming majority of participants commented in some way or another on psychiatric medication side effects, which impacted their daily functioning. These side effects ranged from impairments in sleep, energy, and motivation, to significant neurological, cardiovascular, and endocrine changes. For participants with severe mental illness physical and mental discomfort marked a formation of an environment where their functional impairments made it difficult, and at times
impossible, to undertake other activities, including those related to diabetes management compliance. Participant 03, who is on high doses of antipsychotic medication, described her daily diabetes management activities, as well as the treatment activities associated with her hypertension, high cholesterol, and sleep apnea:

P: I am seeing a nurse and psychiatrist. […] I have pills from psychiatrist, which is clozapine. Pills from my endocrinologist, whom I see on Friday, she gives me Metformin [oral form of medication to treat diabetes], and Insulin [injectable form for people with diabetes]. […] Three of them: Humolog [another type of injectable form of insulin for people with diabetes], Metformin, and Insulin. She also gave me something like a cholesterol...it controls something.

She later describes the discounting of the side effects of the antipsychotic medication by the prescribing psychiatrist:

P: I sleep very well, [pill] puts me sleep at night. But [at the] morning I feel sleepy, but I didn’t think I should tell [clinician] as she has her own idea what I should be like. She is like: “[patient’s name], you cannot be groggy.” … It is not easy [to take] the pills and become goggier at the morning... and this morning I wanted to go, leave it at seven o’clock, and walk to [place]. I couldn’t. I felt very tired, so, I have to pass it till eight o’clock. I am telling [this information to my clinician] and she is telling me nothing, tells me: “you have to keep [taking] the pills.”

The large number of medications often taken by individuals with severe mental illnesses on a daily basis may increase the number of side effects, which may have a negative impact on patients’ mental and physical wellbeing (Megna et al., 2007). Participant 04, a 54-year old single white man diagnosed with schizophrenia, who was described by his clinical team as having “poorly controlled diabetes,” reported strong side effects from multiple medications:

P: One time I was taking thirty pills per day. Every couple of weeks the guy [likely refers to the pharmacist or case worker] comes with a shopping bag of pills, and I tell
[the nurse], “it hurts my stomach, gives me pain in my stomach” [strong emphasis]. And [the nurse said] “these are just little ones, that’s why.”

As these examples demonstrate, for people with severe mental illnesses, medication taking is a complex process. Individual decision-making may be influenced by a patient’s previous and unrelated interactions with the health and psychiatric care systems, and their present context as a person living with mental illness. Clinicians may also discount or fail to address significant side effect distress. These conditions may make it difficult, or at times impossible, for patients to comply with diabetes management recommendations. Therefore, contrary to the depictions in the Conversational Map, taking medications is not a simple act located within a patient’s private sphere of control.

Place: Living in an Organized Space

In this research study, patients with severe mental illnesses overwhelmingly rely on a variety of government subsidized arrangements in relation to housing and income to meet their basic needs. The implications of patients’ living places on diabetes management experiences and choices do not appear on the Conversational Map. However, participants identified these particularities as important components in how they are able to perform diabetes care activities.

Textual Data

In Ontario, there are several government supported strategies developed to help those in need, specifically through financial subsidiaries (e.g., Ontario Works (OW), Ontario Disability Support Program (ODSP), Disability Program through Canadian Pension Plan (CPP Disability)), and housing options (e.g., rent-geared-to-income, supportive housing (SH), etc.) (Canadian Mental Health Association, 2016). In this study, patients’ monthly governmental
assistance was usually calculated per diem, and their living arrangements directly reflected how housing and governmental assistance are organized. The primary source of income for the majority of patient participants was ODSP, which placed them at low-income, which is consistent with other research highlighting that persons with mental illnesses tend to live in poverty (Draine, Salzer, Culhane & Hadley, 2002; Newcomer, 2007; Wilton, 2004). Under ODSP, personal income is calculated through basic needs allowance (Ontario Disability Support Program-Income Support Directives. Chapter 6.2, n.d.). While the ODSP amount varied slightly among participants, in general, those with serious mental health issues often subsist on incomes that are significantly lower than what is needed to cover the cost of basic necessities, such as food, clothing, and housing (Canadian Mental Health Association. Income, 2016).

The level of control patients had over their monthly incomes also varied. For many, a particular portion of their income was directly allocated to the housing provider through a complex set of practices referred to as ‘board and lodge’ strategy, which is used for those residing in supportive housing in Ontario. Also, called boarding homes, supportive housing is arranged under the ODSP to ensure that recipients receive an appropriate board and lodging amount calculated per diem based on their family size and circumstances, with costs shared by the province and the city municipality (Ontario Disability Support Program-Income Support Directives. Chapter 6.2, n.d.) The implications of the board and lodge strategy is the development of a social and economic landscape where the right of patients to receive adequate food and shelter is allocated to a housing provider, who receives a financial allowance based on Basic Need Allowance (BNA) calculations allocated by the government.

Under these arrangements, housing providers are accountable to governmental bodies, but less so to tenants who are expected to pay a fee for accommodation and purchase additional services separately where landlords decide which services they will offer (Basic Needs Allowance, n.d.)
Ontario Disability Support Program-Income Support Directives. Chapter 6.2). Tenants’ social and economic vulnerabilities may also be exacerbated by the unregulated nature of boarding homes. While boarding homes are under the supervision of the province, they do not have a separate set of rules and regulations that would standardize service provision, such as medication dispensing.

Medication Dispensing

Patients with severe mental illnesses identified broad variations in service delivery among housing providers in relation to medication access and dispensing. For some, medication storing and dispensing were completely outside of their personal control, as housing personnel were responsible for these tasks. Participant 10, a 53-year old white man with bipolar disorder, described his medication taking process in his boarding home:

P: [House worker] gives me a breakfast, gives me my medication […], she’s not a nurse, but she’s working at night.

I: How does she know what kind of medication to give you?

P: We got strips! [likely referring to a blister pack here which is assembled and provided by pharmacies] and she knows [medication written] from day to day from Monday to Friday […]

I: Where initially it comes from?

P: I don’t know where it’s coming from. The girl [house worker] has a list with all medications, because I am the only one who is given the medication at the morning

The degree of control that housing personnel have over medication dispensing also varies significantly. In some boarding homes, primarily due to the financial constraints to hire licensed employees who are trained in medication management, housing workers may dispense
medications to residents, but do not intervene or alter medication regimens. Participant 09, a 58-year old white man with schizophrenia who regularly uses a glucometer on regular basis, shared his decision-making process around dosing following blood sugar monitoring:

I: Do you have [medication] in your room?

P: It’s in a blister pack and locked in the kitchen with the staff. Staff gives it to me with my meals, except for lunch, because I never at home.

I: What if [your blood glucose levels change will this] change the number of pills given?

P: I don’t know. I just never tell them.

I: So, you’re mostly taking whatever they give you?

P: Yes.

As demonstrated above, patients’ decision-making behaviors in relation to taking medications are embedded in, and shaped by, the particularities of their living circumstances. Specifically, individual abilities are defined and constrained by rules and regulations in relation to medication access and dispensing in specific boarding homes. This type of contextual and place constraint goes far beyond the schematized understanding of the ease of medication taking that is depicted in the Conversational Map.

Dietary Choices: The Concept of Healthy Eating

On the Conversational Map, compliance with recommended nutrition guidelines by means of a particular diet, and dietary choice surveillance, is referred to as ‘healthy eating.’ Dietary choices are understood as personal acts performed by an individual, and therefore under an individual’s control, inviting the development of targeted strategies and interventions. Eating in a particular
fashion (e.g., the ‘healthy plate’ concept) in line with recommended guidelines is equated with being healthy, as evidenced by the term ‘healthy eating’ itself.

Mapped Realities

On the Conversational Map, ‘healthy eating’ is visually depicted by two pictures. A centrally located picture shows a woman and a man of color sitting at an outdoor picnic table with a large cooler and barbeque nearby. The woman is pouring some water into a glass for the man seated across from her; and on the table, there are four plates filled with salad, vegetables, and fruits. On their right, another picture demonstrates a ‘healthy plate,’ a picture indicating a plate divided into three sections. The largest section is filled with green vegetables, and the two smaller ones filled with ‘meat and alternatives’, and ‘grains and starches.’ A glass of milk and a piece of fruit are depicted beside the plate. The ‘healthy plate’ represents a concept derived from the Canada Food Guide (2007) that recommends specific number of servings of particular food groups per individual. The development of rules around dietary choices dates from the 1940’s, as a result of wartime food rationing, while endeavoring to prevent nutritional deficiencies and to improve the health of Canadians (Canada Food Guide, Health Canada, 2007). Since then the Canada Food Guide (2007) has been transformed numerous times in order to incorporate emerging research evidence, and currently recommends ½ a plate of vegetables, ¼ of grains, and ¼ of meat and alternatives per serving. ‘Milk and Alternatives’ and ‘Fruits’ appear on the side. The Canada Food Guide (2007), similar to other individual-based health approaches, operates on the understanding that health behavior is based on personal choice and preference, and therefore instrumental knowledge on the types of food and portion sizes is important for individuals to enable them to make informed and logical decisions to choose ‘healthy’ over ‘junk’ food.
In line with this understanding, the mapped reality of healthy eating implies that one has the means, ability, and opportunity to follow dietary recommendations in a consistent and routine manner. The operating assumption is that one should display the knowledge of what the right combination of foods are, and then adopt this combination to achieve wellness and stay healthy. Therefore, in the medical literature, dietary choices remain understood as individual acts, largely context-neutral, and individually controlled (Nestle 1998). These medical understandings are taught to patients with severe mental illnesses during regular meetings. Here is an example to illustrate from my onsite observations, along with my memos indicated in brackets:

There are five patients (three women and two men) in today’s group… The group is structured around the Conversational Map, and this session is dedicated to ‘food’. The Map has been unfolded into a large rectangle, and placed on the table. Patients sit around it (for some patients, the Conversational Map is upside down). [……].

*Group Discussions:*

The discussion begins with “types of food”. The major message is that ‘vegetables are good for you’. One patient interrupts with, “I do not like vegetables.” The nurse responds with laughter, and replies “sure, you like McDonalds.” The patient does not respond back.

The nurse poses a question while pointing to the Conversational Map, “What is good for you to eat?” Patients sit quietly. There is limited response. Then the nurse presents illustrated demonstration cards with images of ‘bad’ (e.g., regular coke, doughnut) versus ‘good’ (e.g., vegetables) foods.

The discussion next moves into “types of cooking”. The nurse asks patients about types of cooking. She discusses differences between baking versus frying, and tells them is better to grill instead of frying if ordering take out, and to bake instead of fry if cooking. One of patients, a woman, responds that food is cooked for her [she lives in a boarding home]. The nurse replies with, “‘you should ask them how they cook it, so maybe they can change it.’ The patient does not respond to this. [Memo: Power Imbalance?]
Oblivious to this? Staff won’t change it as they have limited options as well]. Then the nurse discusses portion sizes. She draws a circle on a white board, representing a plate, and explains that half of the plate is supposed to be vegetables, a quarter is meat, and a quarter is carbohydrates.

Then the nurse asks patients to indicated challenges to engaging in healthy eating. Patients do not respond. The nurse tries to suggest some options, such as “Friends who are eating unhealthy food.” The group’s conversation centers on fast food, personal choices, and other people cooking [Memo: again, all about choices, and patients are still the ones who are expected to not to eat with these friends, or ask staff to cook something different for them, or cut their portions]. The nurse states that, “healthy things can also be expensive!” [Memo: but there is no response from patients, and no further discussion on how to manage that expense on incomes limited by government assistance]. The conversation moves into discussion on food groups, and education on what food is preferable to eat.

The group concludes with a brief ‘make your goal’ message, specifically the one around food choices, and arrangement for the next group in 3 months’ time.

In the Conversational Map, the concept of healthy eating is represented as straightforward, autonomous, accessible, and easy to implement. Providers placed important emphasis on how and why particular dietary choices are to be made. Providers also demonstrated a sound knowledge of social constraints, which may potentially affect personal choices (e.g., “expensive,” “cook for you”). Yet, at the same time, clinical practices continued to ignore power imbalances (e.g., asking the patient to speak to the boarding home staff to see if they would change their cooking methods; advising on food preparation, etc.), which were experiences overwhelmingly found in participant’s narratives.
Participants’ Experiences

Healthy Eating in Place and Context

Similar to the social determinants of medication compliance, people with severe mental illnesses identified their living and social environments as determinants framing and shaping their decision-making behaviors around dietary choices when discussing diet as a strategy to manage diabetes. For persons diagnosed with severe mental illnesses, the process of healthy eating was contextually bounded, meaning that it reflected particular financial and housing arrangements. Quotes from several participants highlight the consistent effects of low income on food choices:

P: I spend about […] $200 a month for groceries […] for three people….

I: How do you [manage your groceries on your budget]?

P: I don’t have a choice. Sometimes I do not even eat. I just have coffee at the morning, because I have no food at the house (Participant 06)

…

[Can’t eat healthy] because vegetables cost money. And fruits, you know, everybody should eat those […] but they cost a lot of money (Participant 04)

…

Money! You can’t buy a steak. If you don’t have money, you can’t buy it. Not everybody can afford it […] It’s not my fault, because I was told to take care of myself. I take it personally (Participant 10)

For individuals in boarding homes, the board and lodge amount is directly paid to housing providers who then manage the purchase and preparation of food. Here is how Participant 03, describes the process:
I: Do you do grocery shopping?

P: No grocery shopping. [House workers] do grocery shopping. They buy potatoes and they buy pizza, and buy chicken, rice….

I: How do you decide on money for food?

P: [Boarding home residents] pay three hundred and fifteen [dollars monthly for food from their income support cheques]. It may [increase] at the end of the year.

I: You are paying to whom?

P: [Residents] have a landlord. …We leave at eleven o’clock to [go get groceries] and [boarding home social worker] signs the bill [with the housing provider’s credit card].

Because the budgets that housing workers must work within are a reflection of the financial remuneration provided by the government (Board and Lodge Directive, n.d. ODSP. Chapter 6.4.), they have significant implications for purchasing power. Participant 10 commented:

The money that I get [referring to his ODSP check going directly to his housing provider, who purchases food for the household] is [used] to feed a lot of people. It’s very expensive. You buy like four things [for that many residents] and it’s $50-60.

Participant 09 elaborated on the decision-making around food preparation in board and lodge environments, and the lack of resident options:

I: How is it usually decided what is for dinner?

P: They [boarding home staff] cook. If you don’t like it, [you] don’t eat. No choice. There is a Jamaican [cook] who cooks. You don’t like their food, they don’t care - tough. I don’t blame them. That’s their type of cooking they cook, it’s not Canadian. Some other people don’t like it. It’s a lot of rice. […] A lot of pasta, usually bread, plenty of meat, and usually a salad, or some vegetables, and we can get pierogis, and mash potatoes…. but otherwise, yeah, I just eat what I am given.
When asked, what would happen if a patient wanted something different to eat than what was prepared by boarding home workers, Participant 07, a 66-year-old white woman with schizophrenia, commented:

P: Nah.... [Staff] are not allowed to...they cook [for] the house… pizza, rice ... I don’t like the cooking [here, but] if I am living in your house, I just eat it.

I: [What if] you want a salad?

P: For lunch? No, they do just salad for supper. If [you want] anything you have to go and get it [and] you got to have money.

Participant 04, a 54-year-old white man with schizophrenia, who presumably had more control over food purchasing and preparation because he rented a room with access to a kitchen, also demonstrated barriers to healthy eating because of the place in which he lived:

I have a kitchen that supposed to be mine, I am at the basement, they give me a room [which] is furnished, but there is no key on it. No locking key on my room [so cannot securely store his groceries].

In these examples, healthy eating for a person with severe mental illnesses and diabetes is not an act of an individual will. Dietary choices are determined by, and are formed within, a set of complex housing and governmental arrangements to which patients are involuntarily subjected.

The interviews clearly demonstrated that living environments with their rigid regulatory arrangements constrain and define patients’ food choices. However, over the duration of this project, a surprising and consistent finding was that patients in this study did not simply passively accept the environmental constraints they were subjected to. Instead, patients demonstrated creative strategies that, in turn, influenced and re-shaped their living environments in relation to dietary choices. These creative strategies are next described in more detail.
Participants’ Experiences in the Process of the Healthy Eating

Participants with severe mental illnesses demonstrated wide-ranging accomplishments in activities they were involved in as a part of their efforts to engage in healthy eating. Patients re-shaped their living contexts through practices of acceptance (e.g., dietary choices available through boarding homes), rejection (e.g., reducing portion sizes, and not eating particular types of food), or substitution (e.g., the use of food banks, community kitchens, and so forth). They showed diverse and complex skills and knowledge around processes of locating, accessing, evaluating, and using resources outside of what was available to them through their residences, including food banks, community kitchens, churches, and dedicated community spaces. They also identified these processes as requiring significant instrumental, emotional, and mental investments. They demonstrated an ample degree of effort and dedication, which challenges notions of incapacity, and lack of knowledge, which are often used in clinical practices to explain instances of dietary noncompliance.

“I Go to Places, and that’s how I Eat”

An interesting finding is that the expected linearity of poverty→ boarding house→ no control over grocery selection or meal preparation → unhealthy choice→ diabetes noncompliance was not always assured. Patients demonstrated numerous creative and very complex decision-making behaviors that challenged the organization and limitations of their living contexts. For example, while lack of food choices in a boarding home created an environment of limited food resources, it also prompted some patients to creatively engage in strategies to locate alternative resources, leading to the expansion and strengthening of their social networks.
Patients’ decision-making behaviors in relation to dietary choices developed as a result of their living environments, and their navigation of the domestic environment to meet their basic needs. Patients performed complex, multidirectional, and multidimensional negotiations in relation to dietary choices. These included, but were not limited to knowledge of resources available within their geographic area, ability to access available community places, and familiarity with societal expectations when negotiating access to variety of food resources in the community. In addition to these, patients identified their decision-making as complex work, requiring them to engage in managing their own as well as other peoples’ emotions and actions when accessing food resources at the community. In this study, participants presented themselves as experts who engaged in the aspects of researching, processing, and decision-making in relation to their dietary choices. Participant 10, a white man with bipolar disorder, explained his use of multiple low-cost community-based resources in order to maintain a healthy eating strategy as a part of his diabetes management:

P: I go to...where they serve food [and charge] a dollar, two dollars [for my meal]. Sometimes I go [community kitchen name] there or I go to [name] church, and the other one, the other church at the corner […]. I go to those places, but that’s basically what I eat. That’s how I eat.

I: What kind of food choices do you have there?

P: Whatever they have, used to be beef or chicken, they give us... for sandwich, tuna sandwich, something like that. Those are the choices you have there at those places. Not too many choices.

As Participant 10 suggested, despite knowledge and access to community-based affordable food options, individual patients’ outcomes might still vary, as specific food options may be limited. Participant 06, a 46-year-old white married mother with bipolar disorder, lives with her husband and son in subsidized housing. Her food choices are not circumscribed by housing regulations
regarding grocery purchasing and food preparation. Yet she too still functions within a context
where her dietary choices continue to be overly determined by social institutions, such as
community food banks. She commented:

P: I have to go to the food bank and get some food from there. They give you a free
food, so I go there.

I: What kind of food they usually give?

P: Cheap. They give you shitty [sic] food; garbage. They give you chips, cookies,
pastas…and I cook LOTS [emphasis] of pasta at home. I am Italian, I eat a lot of pasta. I
have way too much pasta. I don’t know [how to feel about it], I had to go to the food
bank, because they [she refers to clinicians] tell me I need good food, but they [now she
talks about food banks] don’t give you what you want, they give you what they want or
what they have. You don’t have a choice [except] just to take it.

These quotes demonstrate that practices of ‘healthy eating’ in people with mental illnesses are
the result of a complex interplay between patient and environment. These complex aspects are
largely overlooked in the road map logic of the Conversational Map, where food choices are
portrayed as context neutral.

**Time: “Can Take up a Whole Day’**

Considerations of time and its role in participants’ diabetes management work is largely
overlooked in the Conversational Map. Participants with severe mental illnesses in this study
demonstrated significant work around activities of diabetes care, alongside managing their daily
demands, which was time consuming, labor intensive, and required substantial time
management skills. Patients described public transportation schedules, costs, accessibility of
stops, and delays as all shaping their diabetes management experiences in relation to their
abilities to reach desired destinations (e.g., appointments, food banks, volunteering, etc.). The
understanding of time commitments and its impact on personal stress levels, which in turn alter diabetes management decision-making behaviors, is not part of medical conversations on diabetes management in severe mental illnesses, and yet it was brought up consistently by patients as an important aspect of their diabetes care. For example, Participant 04, a 54-yo white man with schizophrenia and living in a boarding home, described how he needed to supplement available foodstuffs by visiting community spaces and community kitchens. Consequently, the impacts of commuting, time, and waiting constraints were important attributes in his diabetes management experiences:

P: [Getting to different places] can take the whole day. I mean, depends. If [food bank] start at five o’clock, you have to wait at four [food bank operates on first-come-first-serve basis]. It’s a good part of the day. You have to wait outside before you can actually go in, because of a lot of other people lining up. They’re doing the same thing that you’re doing. Sometimes an hour or an hour and a half [for the wait]. [I go] three times a week, just different places. There is another one [Community Centre which is located in downtown], I go there. Sometimes I go over there, but it requires walking [he lives more west of the city].

Similarly, Participant 08, a 40-year-old woman of color with schizophrenia, described the time and activity burdens associated with the supplementation of her limited food resources:

P: I come from [names residence she lives in]. I go back and forth to [another residence she previously lived in] by trolley.

I: How long does it usually take you to get there?

P: Just an hour twenty minutes one way (pause), once every two weeks. People who used to live there [her previous residence], and got housing somewhere else [can] put their name [on a list], they can come [visit] and [use their food] bank.
These examples indicate that for an individual who has a fairly good and supportive social network with close social ties, accessing food resources may be different compared to somebody who is isolated or does not have consistent social network to rely on.

The Concept of Keeping Active

According to CDA clinical practice guidelines, moderate to high levels of aerobic physical activity and cardiorespiratory fitness are associated with a substantial reduction in morbidity and mortality of diabetes (Sigal et al., 2006; 2013). Therefore, patients with diabetes are encouraged to engage regularly in a variety of physical activities.

Mapped Realities

The Conversational Map visualizes various physical activities using a set of pictures located on the right side down the road, before the finish line. There is a picture of a white man and women riding on a tandem bike, with the man being upfront and the woman behind him, with bike wheels named ‘taking medications,’ ‘healthy eating,’ and ‘regular exercise.’ A white woman is walking on the road and exercising with weights, and another woman is walking a dog. There are two people walking along the fence positioned at the curb of the road. A message on a fence reads, “Do 30 min of aerobic exercise, 5 times per week […] in addition do resistance exercises 3 times per week.” Therefore, the clinical message is that being physically active is important for somebody with diabetes, an understanding clearly articulated by clinicians to patients with mental illnesses during clinical appointments and groups, as confirmed in my interviews and field work. The expectations are for patients to demonstrate the knowledge, motivation, and good use of resources in order to engage regularly in what is pictured on the Conversational Map as a “keeping active” process. Keeping active is viewed as enhancing individual wellbeing,
reducing or eliminating negative diabetic complications, ultimately enhancing overall health, and decreasing the burden on a publicly funded health care system (Sigal et al., 2006).

Physical activity is by no doubts beneficial, however the efficacy of physical activity on diabetes in relation to the type, duration, and frequency that is most beneficial remains unclear. Studies report that unsupervised exercise, which is the type of activity that the vast majority of patients with severe mental illnesses engage in, improves an individual’s glycemic control only if it is combined with dietary intervention, and may in fact be harmful in cases where glycemic control is poor as it may result in hypoglycemia (Sigal et al., 2006). Similar experiences of post-activity hypoglycemia were identified by participants in this study.

Participants’ Experiences

Participants with severe mental illnesses in this study were expected to comply and cooperate with the tasks of being physically active, that is to engage in regular physical activities, defined broadly as both structured through community centers, hospitals, and variety of programs, and unstructured, such as walking. Similar to medication taking and diet following, being physically active was also understood as an individual choice, where decisions and actions are self-contained activities, do not depend on the surrounding physical or social environment, and are therefore context-neutral. However, patients reported different experiences when responding to demands of being physically active. For participants, keeping active referred to a variety of experiences. Only one respondent (Participant 08) directly mentioned physical exercise through structured activity. She described her involvement in yoga classes, which were offered in her apartment building:

I: [What] do you usually do for diabetes?
P: Yoga [is held in] the basement, and anybody can join. When I was living in my other area, I was [also] taking classes, but [instructors] stopped coming to see us [they are volunteers], but now they are coming back.

In this study, patients’ engagement in structured forms of exercise was uncommon. Instead, participants described engaging in physical activity undertaken as part of their daily routines, for example, traveling to mandatory medical appointments, meeting friends, going to the pharmacy, doing grocery shopping, visiting community-based places, working, volunteering, and attending a variety of groups. For participants to fit in another responsibility for diabetes management in terms of adding a structured physical activity appeared to present a challenge.

Despite having numerous demands, patients nonetheless made significant efforts to incorporate medical recommendations of physical activity, but in such a way as to fit in with their daily life. Specifically, people with severe mental illnesses overwhelmingly engaged in walking as a substitute for more structured physical activity. Interestingly enough, walking was used as both a compliance strategy, and as a strategy to manage their monthly budgets, when monies for transportation costs were unavailable. A quote from Participant 10 is illustrative:

I: Why do you walk [to appointments]?

P: I have to. If I want to have pork [for dinner] I have to do that.

I: Can you take TTC [Toronto Transit Commission - the system of public transportation in Toronto]?

P: It’s too expensive, you have to be mindful of those things.

Walking extensive distances, which was often the case for participants in this study, was time consuming and labor-intensive. It also required a particular level of physical and mental stamina, considerations absent from the Conversational Map. Participant 10 detailed in great
length his walking schedule for groceries, appointments, going to the public library, and demonstrating weight loss to clinicians, despite a recent injury:

I: Tell me more how do you [do your groceries]?

P: I walked (laughs). I live, street X and street Y, and the other one is either a [Toronto neighborhood name], or I go to [grocery store name], which is on street B. […….] It requires walking. If I go to the library, it requires walking [……]. It’s hard sometimes. But I try to make a best of what I have […]. I have to show improvement [refers to clinicians]. My weight is […] still high, I can’t seem to bring it down. [Getting food and going to the appointments] have been hard, because I fractured my knee, it makes it hard to get around [he was in a cast and come with a cane for our interview].

In an environment where current evidence of the direct benefits of unstructured physical activities remains unclear, a focus on maintaining a particular level of physical activity as defined by the guidelines may place unrealistic expectations on those diagnosed and set them up for a failure. This is particularly so in the case of a vulnerable population that is already extensively engaging in physical activity out of economic necessity, not personal preference. Regular physical exercise and keeping active is portrayed as pleasurable, ‘good for your diabetes, and good for your health’ type of message, which is freely and easily accessible for anyone anywhere. For people with severe mental illnesses, keeping active is context-specific, in which the constraints of daily life define what activities are available and on what terms. Under these conditions, physical activities such as walking might be quite debilitating and tiring either due to medication side effects and/or to the numerous activities in which patients engage. The concept of keeping active as a self-governing strategy focuses on measurable outcomes (e.g., level of activities, number of hours per day engaged in exercise, number of steps, etc.), which limits the development of real world strategies which may help participants to keep active.
STOP SIX: Finish Line: Achieving Your Goals

In order for diabetes management to be deemed successful, individuals are expected to ‘achieve the goal’ of diabetes management, that is, to have their blood glucose levels within a specific range, and engage in a variety of actions around medication compliance, blood glucose monitoring, healthy eating, and regular physical exercise. The underlying assumption is that if these tasks are achieved, a particular level of wellness will occur.

Mapped Realities

The Conversation Map visualizes completion of diabetes management tasks with a symbolic ribbon crossing, where a motto of ‘My Goals’ is written up. This ribbon is held on both sides, with two members of the health team on the right, and two other supportive individuals (e.g., family, friends, etc.) on the left, with a patient cheerfully crossing it. Here she is depicted as celebrating the achievement of her goals alongside her family, friends, and health care team. This image suggests that diabetes is a condition with a beginning and an end, ultimately resulting in a successful completion when the finish line is reached, bringing joy and happiness to the one who reached it, and those who stand along this journey. Contrary to this image, for patients with severe mental illness, even those who mastered optimal blood glucose control (e.g., Patient 01), this journey is far from over as they continue to face the demands of daily existence. These demands include challenges related to their primary diagnosis of mental illness, being subjected to the particularities of the social context they live in, and continuation of diabetes management activities beyond the stage of ‘achieving your goals.’ Therefore, while there seems to be a cheerful celebration on completion of the diabetes management journey as demonstrated by the Conversational Map, there is no indication of what exactly is being celebrated and further directions.
Participants’ Experiences

Severe mental illness implies that one has a long-standing debilitating condition resulting in functional and social impairment, and that requires significant resources and support on a long-term basis to promote a particular level of functioning. In a clinical environment where capturing the complexity of diabetes management in people with severe mental illness is discouraged in favor of simplified, easily measurable, and observable tasks, patients found their daily living struggles being detached from clinical encounters. This mismatch, at times, left patients discouraged and unengaged in recommended diabetes management tasks. Participant 06, a married mother, reflected on her interactions with health providers when she attempted to discuss her daily struggles at her regular medical appointment:

P: […] They don’t ask you anything like that, no real life, don’t ask that. Just about, strictly about diabetes, they talk about. Yeah. What factors affect you, how you get it, what to do, what not to do.

Therefore, while diabetes management goals are important for both patients and providers, when these goals do not reflect patients’ realities and do not align with their daily priorities, their practical applicability, and most importantly their sustainability in people with severe mental illnesses become questionable. Participant 04, a 54-year-old white man with schizophrenia, shared his experience as a man with a mental illness who additionally lacks permanent housing and any available supports, which has forced him to live on the streets and shelters:

P: [Coughing] It’s been very difficult, very difficult [living] on [the] streets, you know. I never had much...What I had is gone, and I am just trying to live life. If there was a good way to die, I would probably take it, but it’s painful to die. I’d rather die in the hospital. [If] I do not wake up on one of these days, so that’s it. …On the streets... you go to the
park, and you got raccoons, and dogs, you can’t sleep at night. Anyway, 11 o’clock all the lights go on, and police go around there [to eject the homeless from the park].

Irrespective of whether diabetes management goals are achieved or not, patients with severe mental illnesses continue to live a life of struggle and fear, where the reality of being a psychiatric patient with limited resources defines and frames their daily existence. Similarly, Participant 08, a 40-year-old woman of color with schizophrenia, described her life as follows:

P: It’s a struggle… I am forty [years of age], the people I was growing up [with], they’re no longer here. They all passed [away]… I was diagnosed [with mental illness] when I was five [years of age]. That’s why I got in trouble a lot, I got in trouble with my neighbor, I got in trouble with my family, everybody… Living with diabetes is not that easy. Living with mental disorders is not easy… It’s scary. I don’t want to dwell on it. I don’t want to, but I am scared. [Interview was temporarily paused due to her distress]

Living with numerous medical conditions is a struggle, and this struggle may intensify if only limited resources or supports are available, which is often the case for those diagnosed with mental illnesses. The accounts presented in this chapter disclose how housing, governmental assistance, food, exercise and medications are all highly complex issues for participants. The Conversational Map, as it is employed in individual and provider-led group discussions, places the context of diabetes management tasks within an idealized social environment. I have demonstrated how this conceptualization of health work disempowers individuals with severe mental illnesses as it fails to address the issues they encounter and therefore lacks realistic and helpful diabetes management strategies.

Chapter Summary

This chapter presents the experiences of people diagnosed with severe mental illnesses in relation to their diabetes management, and is constructed vis-a-vis the Conversational Map,
which is a visual tool used in the study setting as a guide when working with people with severe mental illnesses. By observing and listening to their stories of everyday practices and activities of diabetes management, and through comparing and contrasting biomedical accounts to those grounded in patients’ experiences, this chapter outlines a very different diabetes management road map. For people with severe mental illnesses diabetes management is experienced as a process fraught with complexity and uncertainty. As context-bound activities, diabetes practices are subject to significant social and material constraints. The current understanding of diabetes management as task-oriented and context-free obscures individual realities consequential to individual success in diabetes management.

The next chapter presents a discussion of key findings, followed by strengths and limitations of this study, and concludes with the implications for policy and practice.
Chapter 6: Changing the Conversation

A Summary of Chapters

The aim of this research project was to gain knowledge regarding experiences of diabetes management in patients with severe mental illnesses who live in a large urban center, and receive diabetes services through a primary care setting, specifically a family health team. Chapter One introduced the study and located it within the broader field of public health. In Chapter Two, I presented a vignette to describe a typical day of a patient diagnosed with diabetes and mental illnesses to set the stage for my further analysis. Chapter Three explored key conversations in the literature around diabetes management to provide an analytical conceptual literature review and to position my research topic. I outlined my research design in Chapter Four, where I discussed data collection, analysis, and strategies employed to ensure the quality of the research.

The main findings of this work are presented in Chapter Five, where through ethnographic and interview-based data I compare and contrast patients’ experiences of diabetes management vis-a-vis the Conversational Map, a visual tool used by clinicians in routine diabetes practices to guide patients in their diabetes care which represents dominant biomedical discourse defining current diabetes care practices. This chapter proves a thick description of patients’ experiences and sets the ground for the data analysis presented further. In my last Chapter, I explore how patients’ experiences with diabetes management are fraught with complexities, which are multidimensional, complex, and changeable. I argue that these experiences are not fully recognized or addressed by practice guidelines. I then offer a strategy to understand and analyze complex attributes of diabetes management where not one road but rather multiple journeys and
detours are possible. I conclude with implications for research, clinical, and policy practices, and what the new insights may bring to our understanding of diabetes management in those diagnosed with mental illnesses.

Findings

There are several important findings I have identified as a result of this study. First, by viewing participants with mental illnesses as experts and active participants in their lives with embodied experiences of illness I was forced to re-think what I came to slowly understand as the limited knowledge of the clinic. In line with previous research, participants demonstrated an ample amount of knowledge in relation to physiological and behavioral aspects of diabetes care; however, they also identified the profound impact of the social determinants of health, such as housing, food security, income, access, social network and support, stigma and isolation in relation to how diabetes care is taken up in their daily realities. However, this insightful expertise of the patients’ voices is not reflected in the Conversational Map as it currently exists.

In exploring diabetes management from the perspective of individuals living with severe mental illness, I found serious omissions and contradictions in the biomedical depiction of successful diabetes management and the related clinical practices I witnessed during study observations. These omissions and contradictions comprise my core findings and the related recommendations that follow.

Attention to omissions and contradictions in my results draws me to the problem of inequity, which is important to critical ethnographic inquiry. My findings demonstrated that diabetes self-care continues to be viewed at the level of individual control, even though the most of this work takes place for my study participants within the confines of the home. It is in this less visible site
that people with diabetes are being targeted to improve their own health as well as that of the larger population. Why the clinical focus is sustained on improving the health work of individuals, and not equally on the social determinants of health, is a curiosity. I found that current diabetes practices continue to operate on a biomedical understanding of diabetes management as an individual responsibility, that is centered around pharmaceutical solutions, further perpetuating stigma for patients who lack the resources and social supports to follow with these recommendations. Moreover, despite recognition of the importance of social determinants of health, clinical recommendations for diabetes care continue to be guided solely and exclusively by biomedically produced evidence. Therefore, while understanding of the social determinants of health in and of itself is not new, they continue to be treated as symptoms. For example, rather than seeing poverty as something to be eradicated, it is often understood as a technical challenge to be managed.

The understanding of diabetes management portrayed by the Conversational Map is in no uncertain terms an idealized representation. While the topics and strategies foregrounded by the map may assist some patients, they may also result in hardship to those diagnosed with severe mental illnesses. Participants in this study experience unstable and chaotic housing arrangements, low income levels, limited control over food and medications, and problems in their relationship to exercise. The obscuration of these and other important issues is significant. The inability to recognize oneself in the approved depiction of diabetes management speaks to a systemic displacement of experience. This lack of acknowledgement may be harmful as it may sustain a sense of social isolation to which these participants were already sensitized. As social isolation is harmful to health, this is an important finding.

The focus on emotional and cognitive control in successful diabetes self-management is a problematic requirement in practice. The very nature of serious mental illness poses
contradictions for this expectation. Some participants related episodes of acute psychosis as well as ongoing feelings of anger, frustration, and loss due to the perceived stigma and social isolation of mental illness. While some sought assistance for their distress, these overtures were not always welcome in the diabetes clinic. Where treatment side effects (e.g., medication related fatigue) impaired clinic attendance, participants were met with punitive financial arrangements that could exacerbate their emotional and cognitive strain. Patients with mental illness experience unique stressors and their capacities to master their emotions may be unrealistic.

My findings confirm that the delivery of theoretical knowledge on diabetes and its care through psycho-education remains prioritized in clinical practices (see also Harper et al., 2013). My on-site observations demonstrated significant material and instrumental work performed by health providers to ensure diabetic education is delivered to those diagnosed with severe mental illnesses. However, I identified incongruence between clinician and patient goals, resulting in a tension between patients and providers, and a lack of attention to the social and material deprivation experienced by people with serious mental illness. My findings demonstrated that the issues and concerns of patients with mental illnesses are often dismissed in clinical encounters, in favor of structured and time-limited education, mandated by regulatory bodies. This presents a significant finding in this study, as such incongruity is problematic for both patients and clinicians. It discourages clinicians from paying adequate attention to the patient’s circumstances, and therefore they lack expertise on how to best intervene. For patients it results in a lack of patient-oriented strategies for success, unintentionally perpetuating the adversity, hardship, and suffering this population is already subjected to.

Other contradictions noted during the course of this work include clinical reporting duties promoted by public health policies. For example, the prioritized collection of glycated hemoglobin, which is a clinical indicator of blood glucose levels over time, may impose an
added burden on patients with mental illness. The requirement to demonstrate successful clinical services through blood tests functions to retain an emphasis on numbers, which abstracts both the people and activities behind these reports. In the organization of these metrics, patients are burdened with extra-appointments that may not be sensitive to their individual health needs. Given the physical, economic, and social labor involved in clinic attendance (e.g., walking long distances to save transit costs), it may be fair to say that patients may be subsidizing the interests of others.

I would argue a better approach is to develop clinical practices that are grounded in the realities of patients’ lives and then chart the path of diabetes management afterwards in relation to those domains. In the section that follows I give credence to the concept of remapping diabetes management experiences. I situate my findings relative to the extant literature. Building on the understanding of patients’ experiences as embedded into their lived realities, I also introduce the concept of detours, comparing and contrasting the expected routes of the diabetes management as outlined by the biomedical practices with the routes patients actually take, to offer a reconceptualization of patients’ practices of navigating complex care expectations.

Mapping Relationships to Previous Research

The knowledge generated from this study supports findings demonstrated in previous work exploring diabetes practices in general and in people with mental illnesses in particular. First, corresponding with findings reported in the biomedical literature (Clark, 2004; Gough & O’Donovan, 2005; Jin et al., 2004), patients in this study identified their diabetes as a physiological deficiency located in their bodies (Participant 01, a 61-year-old man of color with schizophrenia: “it’s in your blood”), and/or as inherited through genetics (Participant 10, a 53-year-old white man with bipolar disorder: “my grandfather had it”). Next, the commonly held
view of diabetes as a lifestyle disease has also been confirmed in my data, similar to how it has been described in the biomedical and psychology-oriented literature (Bushe & Leonard, 2007; Doucet & Beatty, 2010; Thakore et al., 2002). Participants linked their current experiences with diabetes to their past and present behavioral choices, such as “not taking care” (mentioned above Participant 01) of themselves, eating “cheap food” (Participant 07, a 66-year-old white woman with schizophrenia), and “drinking pop” (Participant 02, a 60-year-old man of color with bipolar disorder), echoing the traditional understanding of diabetes as behavior-driven.

Similar to other qualitative work reporting on experiences of diabetes and diabetes management from psychology (Kelleher, 1988; Ockleford et al., 2008), and social science (Daly & McDonald, 1992; Hunt et al., 1998, 2001, 2013; Lawton et al., 2005, 2008; Lutfey et al., 2008; Mendenhall et al., 2012), patients in this study reiterated that diabetes is a complex condition to manage. They described it as a “chore” (Participant 06, a 46-year-old married white woman with bipolar disorder), “work” (Participant 01), and a “fight” (Participant 10). The management of diabetes was repeatedly regarded as time consuming, and emotionally, mentally, and physically demanding. Patients also described that it required significant resources, dedicated prioritization, and a particular level of wellness both cognitively and emotionally where patients were expected to recognize and act on their symptoms (see also Clark et al., 2009; Gomersall et al., 2011; Hunt et al., 2001, 2013; Hindhede, 2014; Lawton et al., 2005, 2008; Loewe et al., 1998; Lowndes, 2012).

Research conducted with people with severe mental illnesses reports high noncompliance rates (Krass, Schieback & Dhippayom, 2015), which are often linked to the lack of insight, and/or cognitive decline associated with mental illness (Velligan et al., 2009). Contrary to that, participants in this study demonstrated sound knowledge around major medical dimensions of diabetes, specifically its physiological and biological aspects, and variety of lifestyle behaviors,
along with main management strategies (e.g., blood glucose monitoring, symptom recognition, appointment attendance, etc.). Patients echoed providers’ explanations of the bio-physiological and behavioral characteristics of diabetes and its prevention/treatment. Among numerous others, they identified strategies such as: “don’t eat cookie” (Participant 01); “walk” (Participant 10); “eat greens” (Participant 03, a 49-year-old woman of colour); “use glucometer” (Participants 01 and 10); attend appointments (Participant 02, a 60-year-old white man with bipolar disorder), and “stay healthy” (Participants 07 and 08). These findings contradict previous research that people with mental illness lack diabetes management knowledge (Shrivastava et al., 2012; Velligan et al., 2009). However, they were in line with more recent findings that people with severe mental illnesses take an active role in their care (Druss, et al., 2002, 2010; Sajatovic et al., 2011), as participants demonstrated knowledge and close involvement in their care.

The literature claims that better diabetes knowledge is associated with better clinical outcomes (Mueser et al., 2002). In line with this understanding, the role of behavioral psychoeducation and pharmaceutical intervention is rarely challenged, and diabetes management continues to be understood as an objective and value-neutral practice. Algorithms, guidelines, assessment forms, and schematizations through flow charts are, of course, useful tools in current health care practices as they have ability to standardize and generalize broad variety of phenomenon to a wider population (Lowndes, 2012). However, their close following often becomes equated with health, where self-management through compliance becomes paramount in clinical practices and a sole focus to ensure individual wellness. If this holds true, one would expect patients in this study to reflect this assumption. However, in the course of this work I identified that patients did not feel hopeful about their health or future relative to diabetes. Current diabetes management is developed through prioritizing one set of indicators over others, which means that standardized forms and assessments do not capture the special needs and experiences in
complex populations (see also Rankin & Campbell, 2006), an understanding also true for people with serious mental illness.

Ruth Lowndes (2012), a nurse working in the field of mental illnesses, and a housing provider in her doctoral work on diabetes-related care practices among 26 women in a rural residential care facility in southern Ontario, brought attention to the regulatory nature of diabetes management and its devastating effects on psychiatric population. She specifically focused on institutional practices, and analyzed through regulatory documentation the ways in which these practices organized and regulated diabetes care in a residential setting. She identified the overarching social relations of resource rationing as potentially contributing to the exacerbation of diabetes among her participants. Her findings pointed to the flaws in the use of diabetes guidelines when applied to those with severe mental illnesses, suggesting that “guidelines do not offer tailored suggestions for diabetes management in impoverished groups, and mandate[d] lifestyle recommendations cannot be met” (Lowndes, 2012, p.193), which my conclusions support.

Furthermore, Lowndes (2012) explored the ways in which policies and regulations organized practices of diabetes management, pointing out contradictions resulting from the prioritization of cost containment over personal wellbeing, and its impact on the exacerbation of illness in this already marginalized population. My research project builds on Lowndes (2012), and continues to focus on the experiences with diabetes management of a marginalized population of individuals diagnosed with severe mental illnesses. It expands, however, to include a broader population of community-dwellers, both men and women, who live in a less institutionalized environment, and therefore are subjected to different contextual practices.
Re-Drawing Diabetes Management Road Map

Providers and policy makers often direct significant resources towards promoting particular aspects in diabetes management, such as self-management through compliance with pharmaceuticals and lifestyle behaviors (Bushe & Leonard, 2007; Janney et al., 2013; Ratliff et al., 2013; Sajatovic et al., 2011), acting on understandings that these are necessary to achieve specific outcomes. This overinvestment in some aspects over others may shift focus away from understanding how diabetes management can result in unintended and negative consequences. My analysis of interviews, observations, and analytic memos enabled me to engage in a different type of conversation, one that builds on an understanding that peoples’ experiences are not separate from their surroundings, and that while that the world around them displays fixed features, these features may change and transform under different circumstances, similar to the way geographic relief is developed.

Schematic maps, such as the Conversational Map, are linear cartograms where some activities are prioritized over the others (Gartner & Radoczky, 2005). This is similar to algorithms and guidelines used in clinical practices and public health policies. The simple, clear, and well-defined features of schematic maps are useful to attain an abstract understanding about destinations, featured rest points and milestones, and overall direction. However, because these maps are created through simplification, they are unable to capture and represent a full range of complexity involved in reality as they are lacking in information about the underlying features of the relief (Bollwerk, 2015). In listening to participants’ stories, reading and re-reading interview accounts, analyzing field notes, and examining clinical practices and regulatory policies, I realized that understanding the complex and multidimensional practices of diabetes management in people with severe mental illnesses required a different map, where more
accurate representation of the surface is available to better guide people to their intended
destination (Klippel, Richter, Barkowsky & Freksa, 2005).

The Treatment Landscape of Diabetes Self-Management

Recently, there has been growing interest in the health field of the role of place and space.
Scholars explored place and space as social, political, economic, and historical fields (Hubbard,
Bartley, Fuller & Kitchin, 2005; Poland, Lehoux, Holmes & Andrews, 2005) that shape people’s
health experiences (Cummins, Curtis, Diez-Roux & Macintyre, 2007; Macintyre, Ellaway &
Cummins, 2002). The role of context in the formation of personal realities has been explored by
social science scholars in the field of disability (DeForge, et al., 2011; Deveau, 2008; Sinding,
2010), HIV (Mykhalovskiy & McCoy, 2002) and mental health (Bourgois et al., 1997; Kontos
et al., 2009, 2010; Moll, 2010). In the field of diabetes, research focusing on poverty (Draine et
al., 2002; Newcomer, 2007; Wilton, 2004) and psychiatric comorbidity (Kyle & Dunn, 2008;
Prince & Prince, 2001) is also well established. In line with other social science scholars, I offer
an alternative to the deterministic approach used in biomedical understandings of diabetes
management through the re-drawing of patients’ experiences as occurring on a relief, upon
particular grounded context. Understanding diabetes management as occurring on a particular
relief (e.g., uneven grounds implicated and formed through complex underlying forces) is useful
to map practical, daily experiences of those diagnosed in relation to their diabetes care within
the context of their daily existence. This re-mapping may help us to understand where diabetes
management as a strategy is failing this and other similarly vulnerable groups of people.

People with severe mental illnesses in this study are overwhelmingly low income and rely on
some type of government assistance, whether it is housing, or income, or both. This assistance is
arranged through the variety of complex regulatory practice that form circumstances in which
people with severe mental illnesses become embedded. Specifically, in Ontario, there are several government programs designed to mitigate economic hardship by providing financial subsidiaries (e.g., Ontario Works [OW], Ontario Disability Support Program [ODSP], Disability Program through Canadian Pension Plan [CPP Disability]), and housing options (e.g., rent-gearred-to-income, supportive housing [SH], long-term care facilities [LTC], etc.) (CMHA, 2016). For example, respondents with severe mental illnesses who lived in subsidized housing (i.e., where tenants do not have to pay more than 30 percent of their before-tax income on rent) reported a wider range of decision-making behaviors around diabetes management, which differed significantly from those who lived in SHs (i.e., boarding homes where housing and financial assistance are combined under ‘board and lodge’ strategy). In this case both funding and housing provider practices have an important impact on patients’ individual choices and may result in different experiences.

The importance of a context, such as living in poverty (Hsu et al., 2012; Hunt et al., 2013); being a member of an ethnic minority group (August & Sorkin, 2011; Capaerchione, Kolt, Tennent & Mummery, 2011; Jones, Trivedi & Ayanian, 2010); being subjected to stigma (Brooks, Rogers, Sanders & Pilgrim, 2015; Schabert et al., 2013); and having difficulty accessing health services (Coblentz et al., 2015) have all been documented as important in diabetes management. These features are conceptualized as determinants, which create a risk to the individual’s ability to comply with diabetes management recommendations. Yet I found that participants with severe mental illnesses do not speak of these elements as ‘determinants’ or ‘risk factors’ that interfere with their ability to perform required behaviors. Instead, they speak to the organization and material circumstances of their lives, which fundamentally shapes the way diabetes management is performed. To demonstrate, study participants identified that living in poverty was an important aspect of their realities of dealing with diabetes, as their dietary
practices were shaped by their experiences of living on a restricted budget, and for some in a regulated physical environment. Participant PB01’s budget constraints shaped his decision-making behaviors in that he bought food “in bulk” defining what dietary options was available at what point. In this example, living in poverty formed a particular relief which shaped and molded his diabetes care experiences. Participants’ experiences with diabetes care were wide-ranging, as their reliefs varied, and in that their decision-making behaviors around diabetes practices varied as well. Their experiences went well beyond simplistic understanding of diabetes care as a set of practices of self-management, and included complex and creative ways in which individuals negotiating their time and space were reflected through their contexts of living. To demonstrate, some participants engaged in volunteer work as a means to improve their dietary options (e.g. participant 09), while others, such as participant 02 (a 60-year-old man of color with bipolar disorder) and participant 04 (a 54-year-old white man with schizophrenia) practices included utilizing multiple community-based organizations as means of reshaping and re-organizing their context of social isolation, and dealing with their emotional health.

Therefore, diabetes management experiences cannot - and should not - be separated from the material life circumstances in which they are enacted. The journey of diabetes management is inseparable from the relief on which it takes place. It requires different types of navigation to scale different roadblocks, resulting in potential detours and experiences in diabetes management.

**Practices of Navigation: Diabetes Management Detours**

Diabetes management is a multidimensional construct where the major burden of care is carried by those diagnosed (Tsotseria, 2013). In addition to this, as pictured in the Conversational Map there is an assumption regarding a supportive and consistent social network available for the
patient to rely upon when carrying out the activities of diabetes management. However, experts note that strong social ties are rarely the case among those with severe mental illnesses (Kawachi & Berkman, 2001). Qualitative research on chronic illnesses identified that managing one’s condition is complex, long-term, and resource-driven, requiring emotional and instrumental investments (Kneck, Klang & Fagerberg, 2012; Pierret, 2003). Similarly, navigating diabetes requires route planning. The shortest distance is not necessarily the easiest route, as rough terrain will likely increase travel time. An accurately drawn map would be useful in order to see the corresponding features on the ground and anticipate difficulty.

A traditional determinants approach in understanding diabetes management would inwardly situate decision-making behaviors as the property of an individual. In line with that, the assumption is that the best outcomes can be achieved with self-management through compliance with pharmaceuticals and lifestyle behaviors (Goldberg et al., 2007; Jeeva, Dickens, Coventry, Bundy & Davies, 2013; Jin & McCrone, 2015; Kouris-Blazos & Wahlgvist, 2007; Frayne et al., 2005; Pendlebury & Holt, 2008, 2010; Mai et al., 2011; Van Dijk et al., 2013). This understanding requires patients to assume full responsibility for the management of their illnesses (Zoffmann, & Kirkevold, 2005). Alternatively, a determinants approach may locate diabetes management outside of participant choice. For example, being homelessness (Hwang & Bugeja, 2000), a member of minority (Maar, Manitowabi, McGregor & Corbiere, 2011), or living in poverty (Chaufan, Constantino & Davis, 2013; Pilkington et al., 2010) become understood as deterministic, where individuals have little power over their circumstances. In both scenarios, the focus is single sided, either on the individual or on structural forces.

Participants with severe mental illnesses demonstrated that diabetes management practices were manifested by way of detours, where participants engaged in diabetes activities in a way relative to their social environments. Specifically, they attempted to reorganize their environments to
suit these needs. For example, one participant meticulously complied with diabetes management activities became closely engaged with his health team as a way of managing his social isolation (“I have no one”) to meet his emotional needs which are not addressed otherwise due to the lack of available support, as evidenced through his description of his social landscape featuring “diabetes and church” as primarily sites of interactions. For a 46-year-old married white woman diagnosed with bipolar disorder (participant 06), her diabetes care realities were embedded into the social milieu of being a low-income married mother with few opportunities to socially dine with her husband, which was important to her. Her purposive decision to eat a sugar-laden donut with him to celebrate their wedding anniversary reflected her lived reality of living in poverty (e.g. an inability to afford eating at a healthy restaurant), where this reality formed a particular diabetes practice (e.g. engaging in a particular dietary decision-making process in order to prioritize, rather creatively, social engagement). In my work I identified that patients’ diabetes management realities were not straightforward and not always aligned with those biomedically understood. In such cases, participants’ decision-making behaviors were perceived as noncompliance with the expectation to be corrected. Contrary to this understanding, participants’ behaviors reflected inherited purposiveness, meaningfulness, and appropriateness to their lived actualities. These experiences went beyond biological and behavioral explanations of compliance. For example, Participant 04 closely followed medication prescriptions, yet did not participate in recommended lifestyle modifications (e.g. physical exercise, dietary options). I also identified that instances of compliance, non-compliance, and departures existed simultaneously, leading me to search for an alternative explanation to understand patients’ practices which are meaningful and strategic, but do not necessarily align with biomedical expectations. By way of demonstration: if we were to understand participant 04’s decision-making processes through these lenses, we would start with the exploration of the attributes directly involved in the formation of his practices. For example, we would conceptualize his
previous contact with the criminal justice system and losing decisional autonomy as aspects which defined participant 04’s understanding of health care, resulting in his present behaviors (e.g. compliance with medications). In line with this, his decision-making behavior of compliance is built on a relief of his knowledge around being penalized if not followed with orders (e.g. “you will see me in shackles”). However, because this is just one of the aspects in how his lived relief is formed, and this formed understanding of being penalized is largely irrelevant to all other aspects of his living (e.g. physical exercise, diet), he is compliant with some aspects of diabetes management but not others.

I would argue that these complex relationships can be better understood through the concept of detours, when patients are engaged in practices of navigation to negotiate and navigate their complex realities. Let us consider a different example from the perspective of detouring. Participant 10 (a 53-year-old white man with bipolar) reported on numerous struggles with diabetes management, where his diabetes was labeled as poorly controlled by care providers, and largely attributed to his inconsistent self-management. However, there is an alternative explanation. Specifically, understanding of his diabetes care as created within a contextually constituted social milieu (e.g. regulated by a governmental subsidiary, bounded by housing financial structure, him being mentally ill and as such subjected to unemployment and poverty). In line with this, participant 10 re-organizes his environment to meet his needs, specifically he volunteers at community places, visits food discount places, and networks to identify new community resources, and then makes decisions around what dietary options to choose (e.g. pasta vs coke in food banks). If one applies biomedical lenses to understand his diabetes experiences then his choices would be understood as instances of noncompliance (e.g. eating starch products) to be corrected. However, these behaviors would be better understood as practices of navigation, or detours, which are developed on a particular relief of living. His
behaviors, and his decision-making processes are not context-free as they are developed as part
of the specific context, which direct and mold his personal actions, as his goal is to meet basic
needs and deescalate the stress, which in turn, is an important part of diabetes management as
well. Similar accounts were identified in other participants’ narratives. For example, a 49-year-
old woman of color with schizophrenia (participant 03) missed her medication dosages in the
morning in an attempt to boost energy to run her daily errands, which also included those related
to diabetes management. Similarly, participant 07 (a 66-year-old single white woman with
schizophrenia) complied with medications as a way of connecting to her housing personnel who
are “as a family” and expected her to take her medications. In the same way as a 40-year-old
woman of color with schizophrenia (participant 08) was eating pasta when visiting “the ladies”
in her previous boarding home as a way of socializing.

In the Conversational Map logic with its embedded biomedical discourse, such complexities
remain unrecognized, contributing to disconnect between diabetes management as instrumental
knowledge and diabetes management as a lived experience. The multiplicity of patients’
realities are not adequately represented in the biomedical view where self-management is
described as a set of discrete steps one can take that lead in a linear way to better health. Instead,
the patients in my study talked about diabetes care and ways of managing it in relation to their
life contexts, in which their choices were at least partially shaped by the social landscape in
which they were embedded. Understanding diabetes management as occurring on and within a
landscape, where multiple detours are possible and should be expected as people operate within
particular milieu may be significant for policy and clinical practices. Looking ahead, future
research may need to integrate more than one perspective in order to incorporate the
relationships that anchor health work.
Strengths and Limitations

This research expands and strengthens what is already known on diabetes management in the population with severe mental illnesses. In addition to other significant findings demonstrated by Lowndes (2012), this work expands its focus by including those living in an urban setting who are subjected to a different set of practices; providing analytical interpretations which are transferable to a broader range of individuals with diabetes management and severe mental illnesses. In line with other scholarly work, this project confirms that diabetes, as a progressive disease, requires significant time and resources (Fonseca, 2009). However, my findings, similar to other social science oriented scholars (Eakin, MacEachen & Clarke, 2003), confirm that peoples’ experiences cannot - and should not be - approached as “blank states” (p.35), but should be understood within the merits of social and historical continuum. The other strength of this work is the range of experiential accounts provided by participants diagnosed with severe mental illnesses in relation to their diabetes management. These narratives provide a thick description and a compelling account for a number of diverse and complex practices of diabetes management, which have not been previously identified or understood. Analytic triangulation of findings drawn from several sources of information, including interviews, nonparticipant observation, and documentation review, provided a comprehensive understanding of the studied phenomenon through different angles. Finally, in line with other social scientists, who argue that the concept of compliance goes beyond medical understanding of following with expert recommendations (Conrad, 1985; Donovan & Blake, 1992; Lerner, 1997; Roberson, 1992; Trostle, 1988), my research also demonstrates that diabetes management experiences in people with severe mental illnesses are not limited to its biological and behavioral dimensions. Instead, my work offers insight into how standardized care practices act to obscure the needs of patients and erase the material circumstances of their lives. Building on this understanding, participants’
experiences and behaviors around diabetes management are re-conceptualized using the metaphor of detouring, an understanding novel in this field.

Potential limitations with this research study include data collected in a single clinic, which may have limited insights on this topic. Over the duration of this project, I have interviewed only patients diagnosed and health professionals who were immediately involved in their diabetes care provision. I have not conducted interviews and observations in any of the secondary institutions drawn into the processes of diabetes care for these patients, such as community centers, food banks, and boarding homes; neither I have interviewed other very important stakeholders who participate in diabetes care for this patients either intentionally or not, such as boarding home personnel, public guardian trustees responsible for money management for these patients, or policy makers and governmental program developers and evaluators. Next, my own position as a woman, clinician and student may have had implications for participant interaction and dialogue. This by no means has had an impact on the kinds of data constructed and analyzed. Therefore, the research findings reported here should be understood as an incomplete exploration, as the choices I made and the phenomena to which I attended may have overlooked other important dimensions of the patient experience.

Study Implications for Clinical Practices and Public Health Policies

Findings in this study demonstrate that diabetes management as currently understood through biological and behavioral perspectives do not fit the reality of people with severe mental illnesses, and this may limit diabetes management effectiveness, inadvertently resulting in poorer clinical outcomes and increasing costs.
Research Directions

I identified that there is a misalignment between diabetes management as understood through biomedical and patient perspectives. Further research should utilize strategies that more broadly allow an understanding of how diabetes management, along with other complex chronic conditions, is bound to a context. Conceptualizing diabetes management through the lenses of social, historical, and political as advocated in my dissertation, may provide a good starting point for a further examination on what aspects of landscape and in which manner form, interact, and impact diabetes care in populations with multiple vulnerabilities. These new understandings may enable a new public health strategy with a particular focus on needs of those diagnosed in a manner sensitive to their living context. However, given the partiality of my research, as no research can ever fully uncover all aspects of the phenomenon, further research should be directed towards critical ethnographic exploration with the participation of other stakeholders playing a key role in diabetes care, such as community workers, allied professionals, community organizations, policy makers, and government officials. Such dialogue will more fully explicate how patients’ experiences connect to extended social relationships and contexts.

Therefore, for future research directions, the inclusion of critical and ethnographically oriented research inquiries to analyze the experiences of patients, specifically those living with chronic and complex conditions, can be beneficial. It will expand health research beyond the consideration of biological and psychological, and bring a more nuanced understanding of the daily complexities that patients face, therefore making research findings more applicable, and more relevant, to patients’ daily lives.
Clinical Practice Directions

Reconceptualization of patients’ experiences of diabetes management may be an important shift for clinical practices for both patients and clinicians.

First, an understanding of complex disease management as embedded into contextual realities will allow health professionals to understand patients’ social and environmental experiences. This may open up further possibilities for future change, going beyond the conventional approach in clinical practices and public health policies, which is to treat diabetes management through its distinct physiological characteristics.

Secondly, approaching disease management from the perspective of multidimensional social complexity will foster an understanding of patient experiences as dynamic. Therefore, patients should be taught and encouraged to assume a role of active contributors to change their treatment landscape. Furthermore, it may also be helpful to shift away from the understanding of people with severe mental illnesses as noncompliant, lacking in insight, and incapable of decision-making or navigating barriers.

Policy Directions

Most importantly, insights from this research suggest a shift away from the exclusive focus on individual accountability in diabetes management, towards incorporating an understanding of choices, decision-making and experiences as molded by context. In my ideal scenario, conceptualizing diabetes management as context-oriented would allow the development of an integrated context-oriented chronic care framework for people with severe mental illnesses, diabetes management clinicians, and policy makers, as well as beyond those fields. Within this framework, the focus would be on the underlying landscape with further policies and practices
put in place to tackle them. For example, if a landscape analysis of a patient context indicates living conditions (e.g., boarding home arrangements, government financial support, social isolation, poverty, etc.) as majorly contributing to individual constraints in achieving health, the development of policies and practices to address these will be enacted. In cases where the full scope of context-level intervention is not feasible due to environmental constrains, knowledge of the underlying landscape of living may help to develop alternative pathways to overcome these obstacles while working on the development of a comprehensive patient-need and context-sensitive system, without resorting to expensive and time consuming behavioral interventions.

Conclusion

To conclude, I would argue that there is a marked discordance between diabetes clinical practices and the lived realities of patients’ who suffer with mental illnesses. Current practices continue to operate on a biomedical understanding of diabetes management as an individual responsibility that is centered on pharmaceutical solutions, further perpetuating stigma and oppression in groups which do not closely attain to these recommendations. Social determinants of health continue to be understood as individual risk factors which are not to be solved but to be managed.

In this critical ethnographic study, using the visual tool of the Conversational Map, I explored how biomedical approach to diabetes management obscures the realities of patients concurrently diagnosed with serious mental illness. Through paying close attention to concepts of science and practice, I identified that there is a misalignment between diabetes management as understood through clinical practices and practice guidelines, and patient perspectives. Through my work I identified that biomedical approach to diabetes management in people with severe mental illnesses overlooks everyday patient concerns, meaning that patient problems remain
undisclosed and unresolved. While the system of diabetic psycho-education is a core intervention, in practice, it does not really work as intended, and is not challenged to change. In this work, I found that positioning diabetes management as a socially constructed phenomenon provides a useful tool for patients, clinicians, and policy makers in re-learning phenomena of diabetes as context-oriented, multidimensional, and amendable. This re-conceptualization fosters a shift away from interventions designed with the image of an idealistic will-based subject in mind.

This work helped me to become more knowledgeable about critical theory and its exciting practical applications that I wish to continue to build on in the future. At the personal level, it has been transformative, both for my program of research and the care that I deliver. Going forward I will focus on physician practices from a critical perspective in order to understand how these practices are socially organized and linked through text, policy, and discourses. My reconceptualization of diabetes management through the introduction of practices of detouring is also a useful strategy for both clinicians and patients in order to decrease stigmatization and enhance empowerment in cases where the inability to follow medical recommendations is often understood as noncompliance.

Through this work I came to a firm conclusion that care practices that centered on the notion of a patient’s individual responsibility may be ineffective or even harmful for marginalized populations, such as people with mental illnesses. I would argue that a next step, based on this insight, would be to develop clinical practices that are based in the realities of patients’ lives rather than based on clinical recommendations developed through epidemiological evidence. This goal could be achieved through building partnerships between clinicians, patients, and social organizations such as Housing, and by placing responsibility on clinicians to learn the realities of their patients’ lives so they can offer treatments that are congruent with those lives.
In summary, future diabetes management strategies in people with severe mental illnesses, if they are truly to provide patient-centered care, need to engage with these social and contextual dimensions of diabetes management, and account for the reciprocity between them.
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Appendices

Appendix I: Conversational Map
Appendix II: Interview Guide I Entry-Level Informants

This interview guide is meant to provide directions for in-depth interview of people diagnosed with diabetes and severe mental illnesses. This is not a manual, and the interview is expected to evolve over the course of interviewing. The aim of institutional ethnography is to gain an understanding of participant everyday experiences with focus on everyday activities.

Interview Guide I

Script: I want to thank you to agree to participate in this study. I am interested to learn what you do on day to day basis to manage your diabetes and mental illness. I will use the term ‘work’ to refer to all activities you do around your medical conditions. Some examples can be what is involved in you taking your medications, what do you do to get prescription, or what tasks you do while being in this (FHT) setting.

In this study we describe it as ‘work’ to show the significance of tasks involved in what you do day-to-day.

Potential Questions

Diabetes care in people with severe mental illnesses
(focus on HOW and WHY).
Tell me what do you do to manage your diabetes day to day? What works for you? What does not work?
Are there specific rules that you have to follow? What kind of rules? How do you know them?
What about your mental illness? Tell me how do you live with both diabetes and mental illness?

Role of people with severe mental illnesses & diabetes management within the organization and their experiences
How do you usually get in touch with Family Health team? What do you have to do?
How do you know what to do? Who do you talk to? Why?
What are the expectations from you? How do you know them?
Tell me about the time when you felt the care was not effective? What did you do? Why?
What major challenges have you encounter?
What would be the most beneficial change in practices from your point of view?

Working around the text (following an actual form if possible)
How were you admitted here? Can you describe it to me?
What kind of documentation you filled out? What did you do with it?
How do you decide what goes into form and what does not?
If you can change it—what would you change in services? How? Why? And what is next? How? Why?
Appendix III: Interview Guide II Health Professionals and Administrators

**Focus:**
1. *the problematic: complexity of two complex conditions and disintegration of care*
2. *role of professionals within the organization*
3. *how diabetes care is delivered by professionals to people diagnosed with severe mental illnesses*
4. *how diabetes care is textually organized within FHT context*

**Introduction:**
I want to thank you for agreeing to participate in this study and to talk about diabetes care for people with severe mental illnesses. I want to start with you. Tell me about yourself and your role in Family Health Team.

**Probes:**
- Can you tell me what your role within Family Health Team is?
- What do you do on day-to-day basis?
- How do you do it?

**The problematic: Complexity and Fragmentation (use Conversational Map as a guide)**
Now I want to discuss what you actually do when you work with your client. I will use this Map just to guide us through the conversation.

**Q1:** If I was an intern here to learn about diabetes care for people with mental illnesses, what would I need to know?

**Probes (focus):**
- How diabetes management for people with severe mental illnesses is incorporated into FHT?
- Are there specific policies or practices that you have to follow while working with this population?
- What are the expectations of the clients? What do you believe are their expectations of you?
- What major challenges have you encounter when working with your typical client, who has diabetes management and severe mental illnesses?
- What changes in practices would be most beneficial for diabetes management for your clients who have severe mental illnesses and diabetes management?

*How is diabetes care for people with severe mental illnesses organized within FHT and what role do professionals play in organizing this care*

**Q2:** Working around texts (based on an actual form if possible)
What kind of documentation should I be filling out? Can you, please, show me?
What are the challenges?

**Q3:** Funding (for administrators)
If I would be trained to be a responsible person for funding what things I should know?
Appendix IV: Recruitment Flyer: People Diagnosed with Severe Mental Illnesses and Diabetes

Dalla Lana School of Public Health
University of Toronto

Have you been diagnosed with diabetes and mental illness?
If so, please consider participating in a research study:
“Diabetes Management for People with Mental Illnesses”

Purpose of Study
To understand how diabetes care for people with mental illnesses works. We hope to learn how people manage their conditions and what influences diabetes care.

What is Involved
- On-site observations
- Initial screen interview (brief, to determine eligibility)
- One-on-one interview (about 90 min long)
- Interviews will take place at a time and place that works for you (interviews can be conducted at other locations besides the clinic if requested)

Who is affiliated with this study
This study is a part of doctoral research conducted by a student in public health sciences at the University of Toronto. She is supervised by Dr. Rohan Ganguli, MD, FRCP(C) at the Dalla Lana School of Public Health, University of Toronto. Dr. Charmaine C. Williams, MSW, PhD, Factor-Inwentash Faculty of Social Work; Dr. Blake Poland, PhD, Dalla Lana School of Public Health, and Dr. Fiona Webster, PhD from the Department of Family and Community Medicine (DFCM) are facilitating strongly needed support and guidance for this project.

Dr. Ganguli can be contacted at: 416-535-8501 ext. 2102 or email Rohan.Ganguli@camh.ca
*If you would like to receive more information about this project and/or interested in participating, please contact

Yuliya Knyahnytska

by email: julia.knyahnytska@mail.utoronto.ca or phone: (647) 247-7781

ALL QUERIES ARE STRICTLY CONFIDENTIAL
(please, be aware that e-mail communication is not 100% secure, please do not provide personal sensitive information over email)
If you have questions about your rights as research participants, please contact Office of Research Ethics (ethics.review@utoronto.ca, 416-946-3273)
Appendix V: Recruitment Flyer: Health Professionals and Administrators

Dalla Lana School of Public Health
University of Toronto

**Have you worked (are you working) with people diagnosed with diabetes and mental illness?**

If so, please consider participating in a research study: “Diabetes Management for People with Mental Illnesses”

**Purpose of Study**

We want to understand how diabetes care for people with severe mental illnesses is organized to develop an analytical map of what impact this care and what does and doesn’t work when providing care for this population. The main purpose is to understand social organization of diabetes management, not to assess effectiveness of clinical care in any way.

**What is Involved**

- On-site observations of day-to-day FHTs operations related to diabetes care for people with severe mental illnesses
- One-on-one interview about 90 min long *(the interviews can be at other locations besides the clinic if requested)*

**Who is affiliated with this study**

This study is a part of doctoral research conducted by a student in public health sciences at the University of Toronto. She is supervised by Dr. Rohan Ganguli, MD, FRCP(C) at the Dalla Lana School of Public Health, University of Toronto. Dr. Charmaine C. Williams, MSW, PhD, Factor-Inwentash Faculty of Social Work; Dr. Blake Poland, PhD, Dalla Lana School of Public Health, and Dr. Fiona Webster, PhD from the Department of Family and Community Medicine (DFCM) are facilitating strongly needed support and guidance for this project.

Dr. Ganguli can be contacted at: 416-535-8501 ext. 2102 or email [Rohan.Ganguli@camh.ca](mailto:Rohan.Ganguli@camh.ca)

*If you would like to receive more information about this project and/or interested in participating, please contact*

**Yuliya Knyahnytska**
by email: [julia.knyahnytska@mail.utoronto.ca](mailto:julia.knyahnytska@mail.utoronto.ca) or phone: (647) 247-7781
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If you have questions about your rights as research participants, please contact Office of Research Ethics (ethics.review@utoronto.ca, 416-946-3273)
Appendix VI: Informational Sheet

Dear Potential Participant,

You are invited to take a part in a research study titled *Out of Sight, Out of Mind: Theory-Based Analysis of Diabetes Management for People with Severe Mental Illness within Family Health Team Setting.*

The purpose of this study is to understand how diabetes care for people with mental illnesses is organized. By hearing from you, we hope to facilitate thoughtful and collaborative dialogue between service receivers and service providers with ultimate aim to improve diabetes care for this population.

This project is a part of doctoral research in public health sciences at the University of Toronto. Dr. Rohan Ganguli, MD, FRCP(C) is a faculty supervisor and a clinical advisor at the Dalla Lana School of Public Health. Dr. Charmaine Williams, RSW, PhD (Factor-Inwentash Faculty of Social Work); Dr. Blake Poland, PhD (Dalla Lana School of Public Health), and Dr. Fiona Webster, PhD (Department of Family and Community Medicine (DFCM)) at the University of Toronto are committee members guiding this project.

This project involves three parts: (1) observation of day to day Family Health Teams operations with focus on diabetes care for people with severe mental illnesses; (2) interviews with those diagnosed with diabetes and severe mental illnesses and health professionals; and (2) analysis of guidelines and policies underlying service delivery.

Observations will be employed over the period of several months to allow researcher to emerge in the setting and to gain in-depth understanding of how phenomena of diabetes care is constructed. Specific safeguard techniques will be put in place to address confidentiality, anonymity and right not to participate/withdraw. Interviews will be conducted at a time and place, which fits participant’s schedules and preferences, including those outside of this particular clinical setting if requested.

Participation in this study is voluntary and all inquiries are strictly confidential. If you have questions about your rights as research participants, please contact Office of Research Ethics (ethics.review@utoronto.ca, 416-946-3273)

If you are willing to participate or want to find out more about this project, please contact me by phone: 647-267-7781 or email: julia.knyahnytska@mail.utoronto.ca

Thank you for considering this request. I am looking forward to hearing from you.

Sincerely,

Yuliya Knyahnytska, MD, MSW, PhD candidate in Health & Behavior Sciences
Dalla Lana School of Public Health, University of Toronto
Appendix VII: Screen Sheet

Introduction:

I want to express my gratitude for your interest in participating in this study. I would like to ask you several generic questions just to get a sense of your life story. Do you agree to go over some question with me?

Screen Sheet:

For People Diagnosed with Diabetes and Severe Mental Illnesses

Screening:
1. How old are you?
2. Do you feel comfortable communicating in English?
3. Have you been diagnosed with diabetes? How long ago?
4. Have you been diagnosed with mental illness? Which one? How long ago?
5. Do you have Substitute Decision Maker in personal care decisions?
6. Will you be willing to share your knowledge about diabetes care?

Eligibility assessing severity of medical condition
I would like to ask you several standardized questions to get a sense on how your medical conditions affect your everyday functioning. [Refer to GAF score guide]

For Health Professionals & Administrators

1. How old are you?
2. What is your role in FHT?
3. How long have you been working as a part of FHT?
4. Do you deal with people diagnosed with diabetes and severe mental illnesses? How often?
5. Will you be willing to participate in one-on-one interview?
Appendix VIII: Observation Guide: Field Work

Field work will be undertaken within FHT setting during regular working hours (Monday to Thursday from 9am to 8pm, Fridays from 9am till 5pm, and Saturdays from 9am till 12pm) to ensure routine operations are captured. In addition to this, observations will be carried out outside of FTH daily operations, such as during visits to dietitian, or participating in diabetes programs, and during off-work hours specific to FHT practices to capture the whole range of regular diabetes management services.

Directions for observations (adopted from Green & Thorogood, 2001)
Acts (brief description of acts)
Activities (of longer duration)
Meanings (verbal accounts that participants use to define what is going on)
Participation (holistic involvement of participants in particular set of actions)
Relationships: who is involved and with whom
Settings: description of the whole setting

Field work within FHT
- Daily ‘routine’ diabetes management related tasks of care providers and clients diagnosed with diabetes & severe mental illnesses who came to the FHT
- Admission, assessment, and discharge planning
- Psycho-educational groups for people with diabetes and severe mental illnesses
- Patterns of activities around diabetes management in which providers and clients engage on day-to-day basis
- Recreational activities if applicable
- Team meetings, clinical rounds, administrative meetings, etc
- One-on-one, telephone consultation
- Diabetes-related procedures: measuring glucose levels, monitoring of physical activities, structuring medical appointments

Field Work outside of FHT
- Consultation with allied professionals outside of FHT related to diabetes management
- Person diagnosed with diabetes and severe mental illnesses daily activities related to diabetes care: going to buy groceries, purchasing medications, using public transportation, etc.
- Recreational activites related to diabetes care

Researcher Role:
My role throughout the observations will be that of an ‘observer,’ where I will ‘enter’ clinical practices related to diabetes management as they unfold. I will emphasize to all participants (diagnosed with severe mental illnesses & diabetes: HPs, and administrators) prior to and throughout observations that my role within the setting is that of a researcher. Additionally, all people involved will be made aware of the voluntary nature of their participation, and that they may choose not to participate at any time. Before asking any questions during observations, it will be made clear to participants that they may choose to ask the researcher to stop observing at any point during the observational studies without question. Field notes will be recorded by the researcher both during and after each observational study on such aspects as physical environment, the people in their various interactions, and social situations, dialogues that take place, daily process of activities, and the researcher’s personal reflections (adopted from Lowdnes, 2012).
Appendix IX: Informed Consent Form for People Diagnosed with Severe Mental Illnesses and Diabetes

Dalla Lana School of Public Health
University of Toronto

Title: Out of Sight, Out of Mind: Theory-Based Analysis of Diabetes Management for People with Severe Mental Illness within Family Health Team setting

Investigator: Yuliya Knyahnytska, PhD candidate, Dalla Lana School of Public Health, University of Toronto

This consent form is only a part of the process of informed consent. Take the time to read this carefully. Feel free to ask any questions. You will receive copy of this form.

Purpose of the Study

You are invited to take part in a research aim to understand how diabetes care works for people with mental illnesses. I ask you to participate, because you have been diagnosed with diabetes and mental illness, and receive service from Family Health Team. By hearing from you, we hope to learn how to make diabetes care more inclusive for people with several chronic conditions.

Study Procedure

Study will include four components.

Component I: Observations. I will observe how diabetes care is delivered to you to understand routine FHT diabetes management practices. You will be asked for your permission to be observed separately at the end of this consent form.

Component II: Interviewing. I will ask you to participate in one-on-one interview which can be performed at other locations beside the clinic if you request. The meeting may take up to 90 min and I will be asking about what you do on day-to-day basis to manage your disorders. I will use information from all interviews to build up the next step of interviewing service providers.

Component III: Care Providers Interviewing. I will also interview service providers to understand how diabetes care works from their perspective.

Component IV: Content Analysis. I will analyze textual material, such as guidelines, medical charts, assessments, etc. to understand the context in which care is designed, delivered and evaluated. By signing this consent form, you agree to give an access to your information, which may be receding in your medical files or assessment documents. Only relevant to diabetes management information will be accessed.
Participation and Withdrawal

Your participation in this study is voluntary. You must have all of your questions answered to your satisfaction before deciding to be in this study. A decision not to participate, a decision to withdraw, or other cessation of participation in this research project will not in any way affect your ongoing or future contacts with any clinic or with any health care facility. You have the right to review, edit or delete digital recordings, the data from research transcripts and/or field notes from your participation in whole or in part. The PhD researcher will review digital recordings or/and transcripts with you upon request, and eliminate data as requested. You can receive the transcript from your participation if that is your preference.

Risks

During the interview, you may find that thinking and answering some of the questions might be upsetting or somewhat embarrassing, and you may experience negative feelings, or feel frustrated. If you have any concerns about the questions you are being asked, please let us know at any point during the study. If you feel highly distressed or emotionally unstable during the interview, the interviewer is obliged to intervene and get you help. Potential interventions may include: ending the interview; contacting your care provider (with your permission and in your presence); escorting you to a relevant community setting, or escorting you to an emergency room.

Benefits

There are no direct benefits associating with your participation in this study. The knowledge gained from this study may be helpful in improving diabetes care for people with mental illnesses and be helpful for health professionals and policy makers in designing and evaluating diabetes related policies and clinical practices.

Reimbursement

You will receive a $25 at the start of each interview to cover travel costs that you may have.

Confidentiality

All information obtained during the study will be held in strict confidence. You will be identified in study files with a study ID only. Your name and other personal identifying information will be stored in an electronically secure database at the Centre for Addiction and Mental Health. No names or identifying information will be used in any publication or presentation. Research records will be kept in locked cabinets at the Centre for Addiction and Mental Health and access will be allowed only to members of the research team.

Observation. You may withdraw your consent on being observed. In this case, no notes on your activities will be made during my observations. You can still participate in interview while withdrawing from observation.

Research records, medical and clinical records, will be kept confidential to the extent permitted by law. The researchers are legally bound to break confidentiality if (1) you being at imminent risk to harming yourself or others; (2) you disclose that a child under the age of 17 being physically, sexually, or psychologically abused.
**Dissemination of Results**

Research findings from this study may be published in professional journals, community reports or presented at professional conferences or community forums; only overall results will be presented; no personal information will be revealed.

**Questions**

If you have any question about this study any time, you can contact:

Yuliya Knyahnytska, student researcher (416) 535-8501, ext 34648 or email: julia.knyahnytska@mail.utoronto.ca OR

Dr. Rohan Ganguli, MD, FRCP(C), supervisor, by phone (416) 535-8501, ext. 2102 or email: Rohan_Ganguli@camh.net

If you have questions about your rights as research participants, please contact Office of Research Ethics (ethics.review@utoronto.ca, 416-946-3273)

**Capacity to Consent**

1. Could you repeat back to me what will happen when we meet for interview?
   - YES____
   - NO____

2. Please, explain what does it mean if you sign this consent form
   - YES____
   - NO____

3. If you decide you don’t want to participate any more, what will happen?
   - YES____
   - NO____

4. If you report you want to hurt yourself or somebody else, what will happen?
   - YES____
   - NO____

*IF YES to all, proceed*

Do you agree to be observed? __________ YES _______ NO

_____________________________          ______________  Signature  ________________  Date
Patient’s Name (Please Print)          Patient          Substitute Decision Maker’s Name

_____________________________
Name

I confirm that I have explained the nature and purpose of the study to the subject names above. I have answered all questions.

_____________________________
Name of Person Obtaining Consent

_____________________________
Signature

_____________________________
Date
Appendix X: Informed Consent Form Health Professionals

Dalla Lana School of Public Health
University of Toronto

Title: Out of Sight, Out of Mind: Theory-Based Analysis of Diabetes Management for People with Severe Mental Illness within Family Health Team setting

Investigator: Yuliya Knyahnytska, PhD candidate, Dalla Lana School of Public Health, University of Toronto

This consent form is only a part of the process of informed consent. If you would like more details about the study or procedures mentioned below, or information not included here, please ask. You will receive copy of this form.

Purpose of the Study

You are invited to take part in a research exploring how policies and ideas about diabetes care in Family Health team affect people diagnosed with diabetes and mental illness. I ask you to participate because you provide service to people diagnosed with diabetes and mental illness. By hearing from you, we hope to learn how to make diabetes care more inclusive for people with multiple chronic conditions.

Study Procedure

Study will include four components.

Component I: Observations. The main focus of this project is to understand social organization of diabetes care. Clinical practices go beyond local setting and are impacted by broader context. Observations will be conducted both on site and off site to gain understanding of routine FHT diabetes management practices. During observation you may be asked questions regarding forms and processes of care as you are performing your routine tasks.

You will be asked for your permission to be observed separately at the end of this consent form.

Component II: Informants Interviewing. Project will begin from interviewing those diagnosed with diabetes and mental illness to gain their perspectives on diabetes care. Identified information will guide interviews with care providers and administrators.

Component III: Care Providers Interviewing. One-on-one interview will be performed at time/location convenient for you. It may be conducted outside of this local setting if this will be your preference. One-on-one interview may take up to 90 min to complete.

Component IV: Content Analysis. Because textual materials are core important in medical practices I will be occasionally seeking clarification and asking questions about how particular form or text is used in FHT.
Participation and Withdrawal

Your participation in this study is voluntary. You must have all of your questions answered to your satisfaction before deciding to be in this study. A decision not to participate, a decision to withdraw, or other cessation of participation in this research project will not in any way affect your ongoing or future contacts with any health care facility. You have the right to review, edit or delete digital recordings, the data from research transcripts and/or field notes from your participation in whole or in part. The PhD researcher will review digital recordings or/and transcripts with you upon request, and eliminate data as requested. You can receive the transcript from your participation if that is your preference.

Risks

During the interview, you may find that thinking and answering some of the questions may leave you frustrated or concerned about potential implications on your professional status within FHT. If you have any concerns about the questions you are being asked, please let us know at any point during the study. It is important to understand that the main focus of this research is not on individuals, but rather on institutional practices, where institution is not a local setting (e.g. FHT) but a structured way of organizing phenomena, as for example discourse, or context. You can always seek clarification from the researcher at the any point of research. If you feel highly distressed or emotionally unstable during the interview, the interviewer is obliged to intervene and get you help. Potential interventions may include: ending the interview; providing de-brief session. The FHT participating in the study would not be named in the report and the details about it described in generic terms, thus preventing a specific FHT being singled out as the source of the observations in this study.

Benefits

There are no direct benefits associating with your participation in this study. The knowledge gained from this study may be helpful in improving diabetes care for people with mental illnesses and be helpful for health professionals and policy makers in designing and evaluating diabetes related policies and clinical practices.

Reimbursement

You will receive a $25 at the start of each interview to cover travel costs that you may have.

Confidentiality

All information obtained during the study will be held in strict confidence. You will be identified in study files with a study ID only. Your name and other personal identifying information will be stored in an electronically secure database at the Centre for Addiction and Mental Health. No names or identifying information will be used in any publication or presentation. All data collected will be anonymized and kept in a double-locked storage cabinet with restricted access. Field notes will not identify you by your position or name. Those to whom you report will not see field notes or transcribed interviews.

*Observation.* You may withdraw your consent on being observed. In this case, no notes on your activities will be made during my observations. You can opt-out from observation part, while still participating in interviews. If during observation of staff meeting/clinical round, etc and
some of the staff who has not agreed to participate in this study is present, the observation of this individual (s) will be withdraw; no notes will be taken regarding this person (s), or this person’s interactions with other team members.

Research records, like other medical and clinical records, will be kept confidential to the extent permitted by law. The researchers are legally bound to break confidentiality when exceptional circumstances are present, including: (1) you being at imminent risk to harming yourself or others; (2) disclosure that a child under the age of 17 being physically, sexually, or psychologically abused.

Dissemination of Results

Research findings from this study may be published in professional journals, community reports or presented at professional conferences or community forums; only overall results will be presented; no personal information will be revealed.

Questions

If you have any question about this study any time, you can contact:

Yuliya Knyahnytska, student researcher (416) 535-8501, ext 34648 or email: julia.knyahnytska@mail.utoronto.ca OR

Dr. Rohan Ganguli, MD, FRCP(C), supervisor, by phone (416) 535-8501, ext. 2102 or email: Rohan_Ganguli@camh.net

If you have questions about your rights as research participants, please contact Office of Research Ethics (ethics.review@utoronto.ca, 416-946-3273)

Consent

Find the opportunity to discuss this study and my questions have been answered to my satisfaction.

I consent to take part in the study with the understanding I may withdraw at any time without affecting my medical care.

I consent to be observed

I consent to be audio taped

I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

Participant’s Name (Please Print)  Signature  Date

I confirm that I have explained the nature and purpose of the study to the subject names above. I have answered all questions.

Name of Person Obtaining Consent  Signature  Date
## Appendix XI: Global Assessment of Functioning (GAF) Scale (DSM - IV Axis V)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description of Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>91 - 100</td>
<td>Person has <strong>no problems</strong> OR has superior functioning in several areas OR is admired and sought after by others due to positive qualities</td>
</tr>
<tr>
<td>81 - 90</td>
<td>Person has <strong>few or no symptoms</strong>. Good functioning in several areas. No more than &quot;everyday&quot; problems or concerns.</td>
</tr>
<tr>
<td>71 - 80</td>
<td>Person has symptoms/problems, but they are <strong>temporary, expectable reactions to stressors</strong>. There is no more than slight impairment in any area of psychological functioning.</td>
</tr>
<tr>
<td>61 - 70</td>
<td><strong>Mild symptoms in one area</strong> OR difficulty in one of the following: social, occupational, or school functioning. BUT, the person is generally functioning pretty well and has some meaningful interpersonal relationships.</td>
</tr>
<tr>
<td>51 - 60</td>
<td><strong>Moderate symptoms</strong> OR moderate difficulty in one of the following: social, occupational, or school functioning.</td>
</tr>
<tr>
<td>41 - 50</td>
<td><strong>Serious symptoms</strong> OR serious impairment in one of the following: social, occupational, or school functioning.</td>
</tr>
<tr>
<td>31 - 40</td>
<td><strong>Some impairment in reality testing</strong> OR impairment in speech and communication OR serious impairment in several of the following: occupational or school functioning, interpersonal relationships, judgment, thinking, or mood.</td>
</tr>
<tr>
<td>21 - 30</td>
<td><strong>Presence of hallucinations or delusions which influence behavior</strong> OR serious impairment in ability to communicate with others OR serious impairment in judgment OR inability to function in almost all areas.</td>
</tr>
<tr>
<td>11 - 20</td>
<td>There is <strong>some danger of harm to self or others</strong> OR occasional failure to maintain personal hygiene OR the person is virtually unable to communicate with others due to being incoherent or mute.</td>
</tr>
<tr>
<td>1 - 10</td>
<td><strong>Persistent danger of harming self or others</strong> OR persistent inability to maintain personal hygiene OR person has made a serious attempt at suicide.</td>
</tr>
</tbody>
</table>
Appendix XII: Field Note Example

Thursday, Sep 9
Arrived 8:45

9:00 am - open doors
Greeting and
Pets started to arrive 8:50 accompanied on their own. I knew what to do... now?

Setting: big bright; counter of 3 PJs behind to
greet and collect info. PJs are leaned
across. 1's popped up from back doors
call for name and introduce themselves. Then

4. Small talk
- asked about fasting
- asked to take off shoes/coat (it repeats several
times, what is this supposed to do)
- collect info (medical) about how of
- explain steps: check BP, check pulse, blood
- sent on medical: eye doctor
- checking PJs
- discuss issues and need to cut down
- etc. go into details

Import in cool, rapid
- send on medical: smoking
- do you plan on cutting up... do I like smoke?
- patient was very young.
- patient getting down on sugar. That's all they said.
- do blood sugar to take blood work.
- pt consistently going back to low BP.
- again, almost constant.
- bp does take blood and talk to the pt.
- pt is distressed by pain.
- pt tries to comfort (?) explain that procedure is almost done.
- got back to as.
- measurements are taken - weight and height.
- pt is in lot of pain.... no response.
- pt requests instructions to get things from RN she does it right.
- pt carries a lot of things to be and has hard time putting them and organizing (don't want to leave them).
- pt is on fluid exam.
- pt has to respond (feed exam) - questions of confusion.
- pt is expected actively cognitively participate to be active in the care.
- does to fast up.
- structure. blood, healthy breakfast, grief.
- Do some procedures w/ red dot. (Same was done before - not was full exam)
- Was mixed up in appointment. Pts are coming up the date, then expected. Informed team, re-structured activities to accommodate.

'Asked about program, where it came from.'

'Answer: Oh, we have developed it.'

- All data (clinical) is imported into EMR system in it's right format when received. It waits for all work to be completed.
- Follow same procedure - weigh, weight, height.
- Go to the computer - check for updates, vaccines, etc.

'2 people'

- All GPs are here.

'Breakfast 9:50': "1 & 20\% to RN. Served by RN."

'Ask to each other today to figure out schedule, etc." Breakfast"

- Another pt comes in (08), asks about food preferences, served.

'At 10 RN. Asked for go for a smoke.'
- Setup: Big room, square table, power point presentation, laptop, and TV tuned to

**Group** 10:05 am. (4-9-19)

- Chatted before to interests, hobbies, list to bring
- Pharmacist showed of...

Intro: Changes in group and logistics
- Group stays the same (preventing of leaving)

Agenda: What diabetes is
How it affects you. Pharmacist brought glucometer to demonstrate.
Shella, intern, explains what she knows about glucose level
RN explains on diabetic info

- Interactions: call clarifies what they talk
- To figure out what type of diet they have

- Explaining blood sugar: some jobs are more involved & understood. Some seems to be very quite and disengaged (why?)
- Ask for guest, expects responses but limited responses, silences (ASS: school???)
working; managing complications; glucometer...
Pharmacist - demonstration of glucometer.
- Patient on water not on a blood. Requires
  stripes.
- Two ft. of reading materials
  or silently setup booking their Free & Charge?

Shelby: Q: what do you think? A: I think it's ok...

It requires technical skills + some sophistication
in use.

At the end, any questions? A: no....

has to be measured between 4-7 am + 5-6 pm → freely
of course! except one

David: how much I should pay for strips?

Ph: free.

And: I show you (on)

Physician comes in

Group 1 in Room

8th. 2 days converted (it's free

physician), asks if I'll have sugar, etc.

Post-operate silent. RN tries to
facilitate guest. GP?

Goal settings

Smile talks about exercise program
(see prep for disabled).

Another pt showed up at the end - served breakfast
- One el refused to talk as she is worried about another el. (RN & GP comforted me.)
- One refused to set up goal
- Shifting up long term goals into smaller tasks.
- RN is increased insisting on setting the goal. (Wrote daily)
- Last arrival & difficult diet (no money from PA)

Next appoint. = Dec 12, 2013

Way for my honor.

Finished food again for those who were late. Can be seen off regardless if willing to wait.

EN gave "goal" noted (and ensured it's filled out "survey" satisfaction). Sheila had hard time understanding I was interpreting to help fill it out. Sheila was not allowed to go see her GP before finishing up survey.

Note: "It took half a day... it's a JOB to do assessments... which is not paid.
I felt very exhausted by info and the intensity of info."
Groups message: “cut down your sugar”
(assuming: sugar is the only cause. Are we supposed to know how to do it what food to eat/not to eat?)

11:30 - D VN

Reflection: Confusion. Morning waiting for
door to open- talked to the 1st (then the appeared
so be in a group. She wasn’t sure about procedure and
reportedly second (?) cautioned (?) ask me (?) what is next
Group: medical info: causes (primarily attributed to
The art + exercising, monitoring / glucometers, symptoms)
and prevention (food, exercise).
- Goal setting (everybody must have a goal. told
[artist] refused / “planning to get it in before”)
- Sorry = make sure everyone answers even
have difficulty).
- Duration: 45 min. (too long?)
- Had an emergency on site before group (another W
went there, couldn’t support group).
- MPs = ask for validation (?) feedback (?) Decision
- About assessor: examiner there? 
- when engaged one-on-one = more effective...
silent in groups
“it’s hard to be focused from 9am to 1130 (some
of clients woke up at 6am to get pills .. .) for them it’s
a fall work day” already.
Setting

- Entrance
- Reception
- Corridors
- Back room
- Office/rooms

Acts

1. Enter
2. Check in w receptionist (ask, name)
3. Wait at the waiting area
4. RN comes, calls name (2 RNs = divided
5. Goes to your room (take B.P., weight, height, need history, feet exam, blad)
6. Goes to back room (print, label, blood to ensure right initials)
7. Enters data into computer
8. Label pt name as "done" -> moves to the next one.

- Flow was interrupted by events: 1) new clients did not show up as was given 2) RN had an emergency, and RN proceeded to emergency call.
Appendix XIII: Reflective Note Example

PB_01 Observations, Metabolic Clinic

Medical Exam:
Computer forms guide the questions asked and information collected. While some ‘small talk’ may be done, largely the conversation evolves around medical terms which are outlined in the form. Interactions are one-way, question-respond. Participant is expected to contribute to this ‘question-response’ conversation, being ‘aware’ of what is asked, be ready to follow directions/conversations which are set up by HPs to get through appointment ‘smoothly’. PB definitely knew what to do and how to do it, he was anticipating the questions and getting ready to the next steps without probing or reminding. It was also interesting that PB takes his blood sugar regularly by the glucometer and he knows what the readings are. He could provide glucometer readings to the HP if asked. Blood test seemed to be a bit distressing as HP had hard time drawing blood from his veins. So, this could have been avoided, but HP continued with the procedure as outlined.

Diabetic Group:
PB is knowledgeable in how to take measurements of his blood sugar, what kind of food to eat and not to eat, and why. He has mastered skills of managing, and has means to ‘manage’ his condition. He also demonstrated particular level of expertise in medication use (e.g. ‘taking insulin can make you fat’). His focus was more on food and eating, which was ‘put aside’ for this session, as it seemed like it was not a part of today’s agenda. Therefore, following agenda is important...even to the expense of what patients were interested in (patient-centered practices??). Reporting of diabetes group is a part of accountability process. Following on patients’ desires/preferences is not.....

Goal setting: during the interview PB mentioned that he is on ODSP and gets only fixed amount of money. He is already very good in managing his scarce resources. Him not having fish is not a matter of not-knowing or un-willingness of doing so, but a matter of not having enough to buy it. Although NONE of this come up, and none of this was asked about. I was wondering how ‘realistic’ or ‘relevant’ these goals to participants who expressed them.

Map: linear simplistic understanding of DM. Assumption behind:
- There is a beginning and the end (‘finish line’ image). Although, diabetes and mental illness are both life-long conditions, there is no ‘finish line’ there
- Only specific aspects are targeted: biological, factors to check (glucose, cholesterol, blood pressure), some psychological (social support), medical signs of high/low level and how to address them and diet (healthy eating) with exercising. Limitations: there is not place to discuss the context: socio-economic, historical, cultural, particular locality. No consideration is given how healthy eating and exercising is achievable for populations who live on a very low fixed budget, on medication which often result in feeling drowsy/sleepy and not having enough of energy to exercise, speaking less about all other demands.
- Diabetes Management is positioned as a centre of ones existence. It involves a lot of different competing tasks, and the expectations are that each diagnosed should make DM the major focus of one’s existence. However, this may be not the case.

Nov 14, 2013
Appendix XIV: Diabetes Flow Chart

<table>
<thead>
<tr>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
</tr>
<tr>
<td>Dyslipidemia</td>
</tr>
<tr>
<td>CAD</td>
</tr>
<tr>
<td>Chronic Kidney Disease</td>
</tr>
<tr>
<td>PAD</td>
</tr>
<tr>
<td>Mental Health Diagnosis</td>
</tr>
<tr>
<td>PCOS</td>
</tr>
<tr>
<td>Foot Disease</td>
</tr>
<tr>
<td>Erectile Dysfunction</td>
</tr>
<tr>
<td>Smoking (#/Day)</td>
</tr>
<tr>
<td>Cessation Encouraged</td>
</tr>
<tr>
<td>Alcohol (any/wk)</td>
</tr>
<tr>
<td>Safe Driving Guidelines Discussed</td>
</tr>
<tr>
<td>Date of last flu vaccine</td>
</tr>
<tr>
<td>Date of last pharmacovaccinal vaccine</td>
</tr>
<tr>
<td>Blood Pressure</td>
</tr>
<tr>
<td>Weight</td>
</tr>
<tr>
<td>Waist Circumference</td>
</tr>
<tr>
<td>BMI</td>
</tr>
<tr>
<td>A1C</td>
</tr>
<tr>
<td>Fasting Plasma Glucose</td>
</tr>
<tr>
<td>LDL</td>
</tr>
<tr>
<td>HDL</td>
</tr>
<tr>
<td>Cholesterol/HDL Ratio</td>
</tr>
<tr>
<td>Diabetes Measures ACR</td>
</tr>
<tr>
<td>eGFR</td>
</tr>
<tr>
<td>Recent Hypoglycemic Episode?</td>
</tr>
<tr>
<td>Date of Last Eye Exam</td>
</tr>
<tr>
<td>Date of Last Foot Exam</td>
</tr>
<tr>
<td>Diabetic Foot Score and Recommendation</td>
</tr>
<tr>
<td>Date of Last ECG</td>
</tr>
<tr>
<td>Driving/Driving Licence Discussion</td>
</tr>
</tbody>
</table>
Appendix XV: Referral Form

CAMH Referral Form to Villas Family Health Team

Patient Must live within the catchment area of Villas to University & Lakeshore to Danforth. Please append consult notes, medication list, and psychiatric report to this form.

Patient Information:
First name __________________________ Last name __________________________
Date of Birth __________________________

Health Card & Version Code # __________________________ (Patient must have a valid health card)

Street Address __________________________ Apt # ________________
Postal Code __________________________ (Patient must live in the catchment area at the top of this form)
Home Phone # __________________________ Cell # __________________________

Case Worker Name __________________________ Case Worker’s Phone # __________________________
Case worker’s email address __________________________

Psychiatrist Name __________________________ Psychiatrist’s Phone # __________________________
Psychiatrist’s email address __________________________

Patient’s Pharmacy/Pharmacist __________________________ Pharmacy Phone # __________________________

Referred By:
Name: __________________________ Date: __________________________

Phone # __________________________ CAMH Program __________________________

Additional Information:
Primary Physical Health Diagnosis:

Primary Mental Health and/or Addiction Diagnosis:

Current medication (attach list if necessary):
1) __________________________ 2) __________________________
3) __________________________ 4) __________________________
5) __________________________ 6) __________________________

CAMH Psychiatry will continue to follow this patient:  Yes  No
If Yes, describe the proposed plan including name/contact # of psychiatrist to share the patient’s care:

______________________________

Appointments scheduling arrangements: (circle one)
Contact patient  Contact patient and Notify case worker  Contact Case Worker
Appendix XVI: My Goals Card

My Goals Card
Living with Diabetes Conversation Map™ Education Tool

Key Points

- Remember what diabetes is and know the myths and facts about diabetes
- Understand your feelings and emotions about diabetes
- Know your numbers and the direction they are going
- Understanding what can cause high or low blood glucose levels for you and checking your blood glucose levels
- You will be able to manage your diabetes with healthy lifestyle choices like healthy eating, keeping active, taking medication, not smoking, and regular diabetes-focused visits with your primary healthcare team
- Is there anything you would like to do differently that would help you manage your diabetes?
- What is your goal?
- What do you need to do before making this change? Examples might include: purchasing a glucose monitor, purchasing a pair of running shoes, or asking a friend to walk with you.
- What is one thing you can do tomorrow that will move you closer to your goal?
- Who will help you?

Know My Numbers and Goals

<table>
<thead>
<tr>
<th></th>
<th>Today's Numbers</th>
<th>My Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood glucose before a meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood glucose 2 hours after a meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A1C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood pressure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cholesterol</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix XV: Program and Services Details

### Program/Service Name:

[Redacted]

### New/Existing:

- [ ] New
- [x] Existing

### Type:

- [x] Chronic Disease Management
- [ ] Health Promotion
- [ ] Prevention
- [ ] Acute/Emergency Care

### Planned Staff Involvement (FTE):

<table>
<thead>
<tr>
<th>Provider</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>RN</td>
<td>0.3</td>
</tr>
<tr>
<td>NP</td>
<td>0.3</td>
</tr>
</tbody>
</table>

### High Level Descriptions & Goals

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1) 70</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) Patients diagnosed with IOVAti diabetes or pre-diabetes, and nation</td>
<td>146</td>
<td>Continued patient recruitment whenever spots available</td>
<td>Patient enrollment in Metabolic Clinic: 75% of all patients in NC by August 2014</td>
<td>The Metabolic Clinic program is part of the VIVA’s Patient-Centered Care, Randomized Effectiveness for Quality Improvement Program</td>
</tr>
<tr>
<td>2) 400</td>
<td></td>
<td>Continued developing education—education maps</td>
<td>Patient attendance: All patients enrolled in Metabolic Clinic will attend at least 75% of the group education sessions and diabetes assessments (3/4 sessions/year) by October 2014</td>
<td>VIVA-PARO Randomized Effectiveness for Quality Improvement Program</td>
</tr>
</tbody>
</table>

### Clinical Practice Guidelines Finalized for Program/Service:

- [ ] Yes
- [ ] No

### Priority Addressed (choose the one most appropriate):

- [ ] Breast Care
- [ ] Diabetes
- [ ] Obesity/Nutrition
- [ ] Smoking/Addictions
- [ ] Mental Health
- [ ] Lung Health
- [ ] Heart Health
- [ ] Other

### Collaboration with other organizations for program/service:

- CAMH
  - St. Joseph’s Chiropractic Clinic
  - CCAC
  - Soo and Be Jean – Dr. Rhonan Furlan
  - Canadian Diabetes Association
  - Liberty Market Pharmacy (Year and Partner)
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diabetes Type II, as well as</strong></td>
<td><em>Corresponding Targets</em></td>
<td><em>Corresponding Targets</em></td>
<td><em>Corresponding Targets</em></td>
</tr>
<tr>
<td><em>Racial Mental Illness (SMI)</em></td>
<td><em>Actual Measure</em></td>
<td><em>Actual Measure</em></td>
<td><em>Actual Measure</em></td>
</tr>
<tr>
<td>1) Offer each qualifying patient the option to take part in group education every 2 months - which indicates the option for peer support.</td>
<td><em>HbA1c reduction:</em></td>
<td><em>HbA1c reduction:</em></td>
<td><em>HbA1c reduction:</em></td>
</tr>
<tr>
<td></td>
<td>- Provide education to patients after fasting blood draw in an example of diabetic nutrition</td>
<td>- Reduce HbA1c by 1% by 2015</td>
<td>- Reduce HbA1c by 1% by 2015</td>
</tr>
<tr>
<td></td>
<td>- Targeted interventions with NPs and MDs in collaboration (education, lifestyle)</td>
<td>- Targeted interventions with NPs and MDs in collaboration (education, lifestyle)</td>
<td>- Targeted interventions with NPs and MDs in collaboration (education, lifestyle)</td>
</tr>
<tr>
<td></td>
<td>- Close follow up by NPs with regards to medication changes, lifestyle interventions and overall diabetes control</td>
<td>- Close follow up by NPs with regards to medication changes, lifestyle interventions and overall diabetes control</td>
<td>- Close follow up by NPs with regards to medication changes, lifestyle interventions and overall diabetes control</td>
</tr>
<tr>
<td></td>
<td>- Referrals for diabetic eye exams and comprehensive foot care</td>
<td>- Referrals for diabetic eye exams and comprehensive foot care</td>
<td>- Referrals for diabetic eye exams and comprehensive foot care</td>
</tr>
<tr>
<td></td>
<td>- Continued work with core measure partners to provide ongoing foot care</td>
<td>- Continued work with core measure partners to provide ongoing foot care</td>
<td>- Continued work with core measure partners to provide ongoing foot care</td>
</tr>
<tr>
<td></td>
<td>- Education and support regarding medication administration (specifically insulin)</td>
<td>- Education and support regarding medication administration (specifically insulin)</td>
<td>- Education and support regarding medication administration (specifically insulin)</td>
</tr>
</tbody>
</table>

**Notes:**
- 119 patients at VFBT (119 patients at VFBT)
### High Level Description & Goals

<table>
<thead>
<tr>
<th>Activity</th>
<th>Performance Measures</th>
<th>Performance Measures</th>
<th>Flexed Quality Improvements</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># of Patients Served</strong></td>
<td>Corresponding Targets (2013/14)</td>
<td>Corresponding Targets (2014/15)</td>
<td>(2014/15)</td>
</tr>
</tbody>
</table>

1. The BIA at VHFRH included an education session attended by 200 diabetes patients. These maps are visual tools that help patients discuss their diabetes. Rizing includes: an overview of diabetes, healthy eating, starting insulin, and diet care. VHFRH has successfully implemented this tool into their lifestyle change education sessions.

2. TBI: Participating in MCC, High A1C of 11.3%. Attempted stabilization of TBI, and frequent follow-up with NMD to adjust insulin, review BG readings, and provide lifestyle counseling. Made efforts to fix incorporating more vegetables (mainly fruits), and worked to increase physical activity. Within three months, the patient's A1C went from 11.3% to 7.3% (normal). The patient attended the metabolic clinic, and managed their insulin and CHF independently. As of today, TBI remains within normal A1C levels despite his weight loss. He is an active participant in his care and works to further bring down his A1C to target <7%.

3. Collaboration with CAMH—selected 6 patients to CAMH lifestyle study. We are excited to take on a more active role in their care. We are able to share experiences with lifestyle modification during group discussions, etc.

*For more information, please consult the shared links.*

**Patient encounters may include but are not limited to in-person appointments, telephone contacts, OND and home visits. Group sessions should count each participant in each session as a patient encounter.**

Programs share the following characteristics: a) specific patient group, b) meaningful, nutrition-related objectives/indicators, and c) outcome measures/indicators that allow the PIH to determine whether the objectives have been achieved.
Appendix XVIII: Conversational Map Mapped Coding