

ATHABASCA UNIVERSITY

TYPE 1 DIABETES AND EMOTIONAL LABOUR IN YOUNG ADULTS:
INTERPRETIVE PHENOMENOLOGICAL ANALYSIS

BY

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF HEALTH STUDIES

FACULTY OF HEALTH DISCIPLINES

ATHABASCA, ALBERTA

MAY, 2022

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Approval of Thesis

The undersigned certify that they have read the thesis entitled

**TYPE 1 DIABETES AND EMOTIONAL LABOUR IN YOUNG ADULTS:
AN INTERPRETIVE PHENOMENOLOGICAL ANALYSIS**

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In partial fulfillment of the requirements for the degree of

Master of Health Studies

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Dedication

To my father, Čika Ljubiša, and Deda Moma.

Acknowledgement

This project is the culmination of what feels like a life-long journey trying to untangle the many facets of living with type 1 (T1) diabetes, and yet it would not have been possible without the support of so many. Whether that support came in the form of an encouraging word, a willing sounding board, or a rallying cry to reaffirm that this project is, indeed, important, I am incredibly grateful to you all. It truly takes a village.

First and foremost, there are three people to whom this research project is deeply indebted: First, Dr. Katie Kilroy-Marac of the University of Toronto, who was the first to embolden me to set on this path. It was during my doctorate degree coursework that the seed for this project was first planted, in Dr. Kilroy-Marac's anthropology course on haunting, of all things! And yet, it could not have made more sense; chronic illness is a thing that haunts. I had simply never anticipated that *haunting* would be the lens through which my personal struggle with T1 diabetes would finally make sense to me. Second, to my wonderful supervisors, Dr. Karen Cook and Dr. Gwen Rempel: you have been some of the most supportive, personable, and compassionate voices I have had the pleasure of collaborating with. Your guidance has been invaluable, and your feedback has allowed me to filter through the white noise of imposter syndrome and stay the course. For the first time in my graduate career, I can confidently say that I really believed in myself; under your tutelage, my aspirations for this project never once wavered.

I must also thank the wonderful endocrinology team (current and former) at Sick Kids Hospital in Toronto, as well as my diabetes care team from Mackenzie Health: Dr. Jacqueline Curtis, Marcia Frank, Margo Small, Dr. Ruth Slater, Dr. Nathalie Leung, Sarah Verbanac, and Julie Sartori. You have been vital not only to my health but have

provided me with so much wisdom and insight into the world of endocrinology. Without the education you have given me, and more recently, your active participation in the germination of this research project, none of this would have been possible. I hope from the bottom of my heart that the knowledge produced here will come back to benefit the many young patients you see every day, both at present and in the future.

I must also extend my gratitude to the people and organizations who showed enthusiasm for my research. I am so appreciative for the Juvenile Diabetes Research Fund for everything they do for people living with T1 diabetes. Furthermore, thank you to Dr. Bruce Perkins and Madison Taylor from Toronto General Hospital, who facilitated recruitment by introducing me to ConneCT1D.

Writing this on the eve of our third year into the COVID-19 pandemic, much of my continued resilience is owed to those closest to me. I am incredibly grateful for my partner, Brenton Buchanan, who knows well the trials and tribulations of the graduate student. Thank you for being my sounding board and my rock through this project and all the others. You have always helped me articulate my thoughts when they are at their most garbled. Thank you, as well, to Malorie Nilson, who has always been ready to lend an ear and read a passage of my first draft drivels. I am indebted to our many conversations about chronic illness and have no doubt that they have bestowed me with many sparks of inspiration. To my friend and literary agent, Dr. Emmy Higdon: thank you for helping me navigate some of the finer details of the health sciences. As someone whose home has been the humanities for the better part of a decade, your insights and advice have helped me acclimate to my new discipline. I must also extend thanks to my furry family: my rescue cats, Moonstone and Peanut Butter. While neither of you care for

why I sit in front of a shiny rectangle all day, tippy typing as though my life depends on it, I am grateful for your adorable butts blockading my keyboard and shedding fur into my coffee. It's good to remember that other things exist! Finally, thank you to my parents, who have watched me live out my worst years with T1 diabetes and have endured to witness something truly incredible bloom from those trials. I am proud of us.

Last but certainly not least, this acknowledgment page would not be complete without dedicated space for my nine brave participants who took time out of their lives to share their experiences with me. Thank you for trusting and collaborating with me to produce this research. I enjoyed speaking with every one of you. I know that finding others with T1 diabetes is like spotting a unicorn in the wild, so you can only imagine how thrilled I am to have found a whopping nine unicorns. What a brilliant and colourful herd we'd make!

Abstract

Existing scholarship on the intersection of T1 diabetes management, its accompanying psychosocial challenges, and mental health repercussions informs my work, which examines whether young adults with T1 diabetes experience emotional labour, and if the concept can deepen understandings of living with diabetes. Current research shows that emotional labour has not been applied to transitioning youth with T1 diabetes, though it has been employed in other disciplines to explore the experiences of racially marginalized groups. Using Interpretive Phenomenological Analysis, I identified themes that constituted sources of emotional labour, as participants readily understood emotional labour to be inherent to diabetes management. The over-expenditure of emotional labour suggests profound implications for mental health outcomes and diabetes distress levels, and participant experiences revealed institutionally imbedded ableism that elicited even further expenditure of emotional labour. Research findings suggest that reconsideration of educational frameworks and praxis within diabetes healthcare may alleviate emotional labour and diabetes distress.

Keywords: type 1 diabetes, young adult, emotional labour, diabetes distress, mental health, eating disorders, diabulimia, disordered eating

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Chapter 1. Introduction (or Significance of the Problem)

Background

Type 1 (T1) diabetes is a life-long metabolic illness that renders the body unable to metabolize glucose. As a result, patients must manage their blood glucose levels with synthetic insulin, diet, and exercise. Also known as juvenile diabetes, T1 patients are usually diagnosed in childhood, adolescence, and young adulthood, the latter two of which are considered phases of increased psychological vulnerability. Because T1 diabetes requires round-the-clock, rigorous management, many young adult patients struggle with non-adherence, increased psychological distress, mental health challenges, social stigmatization, and poorer outcomes for eating disorders. These findings have been consistent over the last several decades (Johnson, 1980), though more recent scholarship has provided a clearer picture of psychosocial challenges for T1 diabetics, including higher risk of major depressive disorder, suicidal ideation, generalized anxiety, eating disorders, social stigma, and what researchers are now calling diabetes distress (Berry et al., 2015; Candler et al., 2018; Colton et al., 2015a, 2015b; Ferro et al., 2016; Ferro, 2017; Fisher et al., 2012, 2015, 2016; Gagnon et al., 2017; Gonclaves et al., 2016; Jeong et al., 2018). In my thesis research I will study the relationship between T1 diabetes management and emotional labour based on my critical examination and synthesis of relevant research, including major findings, themes, and concepts. I will address gaps in the existing literature through an interpretive phenomenological analysis.

Statement of Problem

There is evidence that T1 diabetes is linked with increased psychosocial challenges that impact mental health and health regime adherence (Robinson et al., 2018). Clinical depression, anxiety, eating disorders, social stigmatization, and ‘diabetes distress’ are common and well-recognized repercussions of these psychosocial challenges and long-term

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diabetes management, especially in young adults (Berry et al., 2015; Colton., 2015; Ferro, 2016; Jeong et al., 2018). The literature to now has focused strictly on the correlation between T1 diabetes and mental illness, T1 diabetes and psychosocial challenges, and has suggested new ways of understanding distress particular to T1 diabetes (Fisher & Polonsky, 2005-15). However, research has yet to provide evidence and subsequent theory development about the psychosocial challenges that instigate such high occurrence of distress in young adults with T1 diabetes.

Research Questions

1. Do young adults with T1 diabetes experience high levels of emotional labour?
2. Can the concepts of emotional labour be used to deepen understandings of why young adults with T1 diabetes experience increased risk of psychosocial challenges?

Key Concepts

Emotional Labour

Emotional labour is defined as the process of managing feelings and expressions to fulfill the emotional requirements of a role or task (Hochschild, 2012). Emotional labour includes negotiating how emotions are processed, expressed, or sometimes all together suppressed. In the context of the proposed research, the ‘role’ or ‘task’ is the ongoing management of T1 diabetes, such as insulin bolus calculations, bolus corrections, glucose testing, and carbohydrate counting, ratio and adjusting. These constitute the physical and cognitive labour of diabetes management. The related affective processes that go unseen and uncommunicated constitute the emotional labour of diabetes management, and often occur in tandem with managing blood glucose. Examples of this may include attending to details, endeavouring to be aware and present, remembering to check blood glucose, making the effort to make calculations in the first place (this does not refer to the calculation itself),

managing negative feelings that may arise as a product of diabetes management, mitigating concern from loved ones, coping with social stigma, and explaining the illness to laypeople.

Diabetes Distress

Diabetes distress is defined as a rational response to the life-changing qualities of diabetes. It is distinct from other forms of clinical depression in that its causes are firmly rooted in the challenges of diabetes management (Berry et al., 2015). The expert committee of the Diabetes Canada Clinical Practice Guidelines characterizes diabetes distress as, “the despondency and emotional turmoil specifically related to the need for continual monitoring and treatment, persistent concerns about complications, and the potential erosion of personal and professional relationships” (Robinson et al., 2018, p. 130).

Diabulimia

Diabulimia, although an unofficial term, describes the willful restriction of insulin by diabetic patients to induce weight loss (Chelvanayagam & James, 2018). Diabulimia is understood as synonymous to bulimia nervosa; insulin restriction is considered a form of purging, and patients often, but not always, demonstrate disordered eating, including bingeing (J. Curtis, personal communication, January 29, 2020).

HbA_{1c} or Glycohemoglobin Test

HbA_{1c} or glycohemoglobin test is commonly used to evaluate how well patients with diabetes are managing their blood glucose. The test measures the amount of glucose bound to the hemoglobin in the rest blood cells, and people with diabetes will naturally have more glucose bound to hemoglobin as a result of elevated blood sugars. Individuals without diabetes have an HbA_{1c} of below 6%; an A_{1c} of 6.1-5.4% constitutes ‘pre-diabetes,’ and an A_{1c} of 6.5% indicates diabetes mellitus. Currently, the Canadian Diabetes Association recommends an HbA_{1c} of 7.0% and below for patients with both T1 and T2 diabetes (Lipscombe et al., 2018).

Study Purpose

The purpose of this study was to establish emotional labour as a viable concept for deepening understandings of the links between T1 diabetes management, psychosocial challenges, and mental health complications. I sought to determine whether young adults with T1 diabetes experience high amounts of emotional labour; whether they relate to this concept.

To discover whether high amounts of emotional labour is experienced by study participants, major sources of diabetes-related distress should first be identified using models from previous studies, such as those of Jeong et al. (2018) as well as Fisher and Polonsky's research and development of the Diabetes Distress Scale (Fisher et al., 2012; Fisher et al., 2015; Polonsky et al., 2005). Descriptions of what may qualify as emotional labour in relation to these stressors could then be established. However, some flexibility was maintained, as emotional labour may present differently for different people, and it may furthermore be communicated differently.

In interviewing participants about emotional labour in relation to these stressors, I intended to gain a deeper understanding of why and how these stressors compromise patients' mental health. In other words, the participants had the opportunity to introspect and determine if diabetes-related stressors demanded high levels of emotional labour, which could otherwise be invested elsewhere to improve quality of life.

Chapter 2. Review of the Literature

Introduction

Despite vast improvements in treatment, T1 diabetes remains a challenging illness to manage, especially in young adults. HbA_{1c} results in young adults (ages 15-25) with T1 diabetes have worsened over the past 5-7 years, with the average HbA_{1c} increasing from 7.8% to 8.4% (Foster et al., 2019). To explain poor control and non-adherence, there is growing research on T1 diabetes in young adults, psychosocial challenges, and mental health, though these issues are not new. Explanations for poor control and non-adherence have long been sought. Johnson (1980) published a review of existing literature on the psychosocial factors in T1 diabetes, but the findings are largely outdated and fortunately less relevant in our current era of diabetes knowledge and research. These included an emphasis on the inevitability of complications due to inadequate treatment options, speculation that diabetes is caused by deviant temperaments, and the problem of painful injections (Johnson, 1980). Similarly, Hopper (1981) published a study in *Social Science and Medicine* on the relationship between diabetes, stigma, with consideration of cultural, social and economic variables, though her findings are not useful and echo outdated beliefs on the link between problematic temperaments and chronic illness. Because diabetes treatment is ever-evolving, the material conditions of the illness change rapidly and render studies even a decade old inapplicable to current patients. For this reason, the literature review to inform my thesis research focused on several recent but important studies, and a major review done by the Diabetes Canada Clinical Practice Guidelines Expert Committee (2018).

T1 Diabetes and Mental Health

Current research on T1 diabetes and mental health has demonstrated increased incidence of psychological distress, mental health challenges, and stigmatization. Canadian researcher Mark Ferro (2016) found that young adults (ages 15-30) who self-reported having

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a chronic health condition were at higher risk of experiencing clinical depression and suicidal thoughts than non-chronically ill controls using data from the Canadian Community Health Survey – Mental Health. His study on major depressive disorder, suicidal behavior, bipolar disorder, and general anxiety disorder among what he terms ‘emerging adults’ with and without chronic health conditions found that “lifetime prevalence of mental disorder was significantly higher for individuals with chronic health conditions compared with healthy controls,” and that “physical and mental comorbidity is prevalent among emerging adults” (Ferro, 2016, p. 462).

Chronic health conditions were defined as those with a duration of or longer than six months and diagnosed by a health care professional. Ferro (2016) used the WHO International Classification of Disease 10th Revision (ICD-10) and included five categories of chronic health conditions, one of which was endocrine/digestive and included diabetes and bowel disease (Ferro, 2016). The results showed that males between the ages of 15-30 with endocrine/digestive conditions were significantly more likely to suffer from lifetime prevalence of major depressive disorder (33.5%) and suicidal behavior (39.7%) compared to controls and those with other chronic conditions. Furthermore, both males and females with endocrine/digestive conditions were at increased risk for major depressive disorder and suicidal behavior (Ferro, 2016, p. 465).

Ferro obtained his data from a 2012 national epidemiological study from Statistics Canada and used a multistage stratified cluster sampling design with a representative sample of $n = 25\,113$ (Ferro, 2016, p. 463). A second study by Ferro et al. (2017) using the same large data set found that young adults with chronic illnesses were not only more likely to report mood disorders, drug disorders, comorbid mood disorders, and comorbid drug disorders, but were also more likely to identify as female and be of lower socio-economic status (Ferro et al., 2017, p. 848). The intersection of chronic illness with other disadvantaged

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demographic categories revealed the extent to which these populations are vulnerable to psychosocial challenges.

One of the limitations of Ferro and colleagues' studies is that they cannot establish causation between chronic illness and mental health complications due to their cross-sectional designs. Furthermore, because diabetic participants and those with bowel disease shared a single category (endocrine/digestive disorders), it is difficult to know to what extent Ferro's findings are generalizable to diabetic populations. Similarly, his study did not differentiate between T1 and T2 diabetes, which can require vastly different treatment regimens and deviate in some of the psychosocial challenges they present.

Nonetheless, Ferro's findings are supported by the 2018 Diabetes Canada Clinical Practice Guidelines for diabetes and mental health, which reviewed 230 related studies. The Clinical Practice Guidelines identified several mental health challenges associated with T1 and T2 diabetes, including a 30% prevalence of depressive symptoms and twice as much major depressive disorder (10%) compared to other chronic illnesses. Furthermore, the risk of experiencing depression was found to increase with the duration of illness. Diabetes diagnosis was associated with a doubling of antidepressant prescriptions, where undiagnosed diabetes was not, suggesting that the depression is linked to aspects of diabetes management (Robinson, et al., 2018). Furthermore, depressive episodes were more likely to last longer and recur in people with diabetes compared to those with other chronic illnesses. Anxiety was reported as comorbid with depressive symptoms, with one study showing that approximately 14% of patients with diabetes struggled with generalized anxiety disorder; 28% suffered from subclinical anxiety disorder, and 42% reported experiencing some anxiety symptoms (Robinson, et al., 2018).

Although the research has been consistent in its findings correlating depression, anxiety, and diabetes, it is worth noting that understanding mental illness as comorbid to

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diabetes may obscure the ways in which mental health challenges arise as a direct result of the complicated conditions of diabetes management. For example, it is worth questioning whether understandings of major depressive disorder in the general population are generalizable to chronically ill populations, and how this generalization may deprive chronically ill patients of specific treatments tailored for their unique challenges. As such, the framework of ‘comorbidity’ may be inadequate to fully address the particular ways in which people with chronic illness experience mental health challenges. Some researchers have proposed a new approach to treating mental health concerns in patients with diabetes by introducing the notion of *diabetes distress* as something distinct from clinical diagnoses of mood disorders (Fisher et al., 2008; Fisher and Polonsky et al., 2012; Fisher et al., 2015; Polonsky et al., 2005). *Diabetes distress* removes the framework of comorbidity by qualifying it as an organic outgrowth of living with diabetes. In other words, the patient would not experience symptoms of depression and anxiety if not for their diabetes.

T1 Diabetes and Eating Disorders

Although diabulimia is a commonly used term among healthcare professionals and researchers, there is no separate diagnostic code for diabulimia. The official and correct medical term is “eating disorder with T1 diabetes” (Chelvanayagam & James, 2018, p. 980), and the condition is diagnosed using criteria for conventional eating disorders. The DSM-5 classifies insulin omission as a purging behaviour (J. Curtis, personal communication, January 29, 2020), and this often results in a diagnosis of bulimia nervosa or a purging disorder. Furthermore, if the patient is restricting both food and insulin, they may be diagnosed with anorexia nervosa (J. Curtis, personal communication, January 29, 2020). Patients may control weight through insulin omission and food restriction, however, a return to advised insulin regimens result in the weight being regained, which then reinforces the cycle of omitting or restricting insulin (Falcao & Francisco, 2017). Individuals with T1

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diabetes and eating disorders are at increased risk of poor glycemic control, diabetic ketoacidosis, and diabetes complications such as retinopathy (Larrañaga et al, 2011). Furthermore, insulin restriction has been associated with a threefold increased risk of mortality for women (Goebel-Fabbri et al, 2008).

It is generally accepted that patients with diabetes are at higher risk of developing eating disorders. According to Robinson et al. (2018), anorexia nervosa, bulimia nervosa, and binge-eating disorder are more common in patients with diabetes than in the general population. Furthermore, research has shown that eating attitudes and behaviours defined as subclinical are almost twice as prevalent in young women with diabetes compared with non-diabetic controls (Goncalves et al., 2016). Chelvanayagam and James (2018) have noted that research indicates that up to 20% of women with T1 diabetes struggle with diabulimia.

However, much of the examined research on diabetes and eating disorders lack a consistent framework and definition. All studies examined for this literature review used the terms ‘eating disorder’ and ‘diabulimia’ interchangeably and did not distinguish between the two. Diabulimia was unanimously understood as a type of bulimia nervosa, and the same criteria for diagnosing bulimia nervosa was used for diagnosing diabulimia.

Gonçalves et al. (2016) used the term ‘disordered eating’ multiple times without definition, even though it is deemed a “common psychological problem in people with T1 diabetes” (p. 153). Furthermore, Gonçalves et al. used the Eating Disorders Examination Questionnaire to evaluate the diabetic participants without consideration being given to the ways that people with diabetes may require a different evaluation or approach than those who do not have diabetes. This measure was developed with a community sample and a patient sample, 36 women with bulimia nervosa or anorexia nervosa (Fairburn & Beglin, 1994). In turn, this informs the study’s objective: “To evaluate dysfunctional eating behaviours...in adolescents with T1 diabetes” (Gonçalves et al., 2016, p. 152). Rather than clearly defining

dysfunctional eating behaviours in a way that is specific to diabetes, they are assumed universally generalizable to both diabetics and non-diabetics.

Candler et al. (2018) does define disordered eating behaviours, but the definition does not include behaviours particular to people with diabetes despite the term being generalized to diabetic populations. Furthermore, both Candler et al. (2018) and Gonçalves et al. (2016) use the following phrases to describe the mentality of patients with diabulimia: “over evaluation of weight, shape, and their control” (Candler et al., 2018, p. 119), and “constant food pre-occupation” (Gonçalves et al., 2016, p. 153). The criteria for these preoccupations and over-evaluations were not defined, but rather assumed, which reflects a universalized understanding of what comprises healthy self-perception. Implicitly, then, the researchers assume that what constitutes ‘healthy self-perception’ must be applicable to both chronically ill and non-chronically ill populations.

Similar assumptions can be seen in the work of Patricia Colton who led two studies, both published in 2015. Colton et al. (2015a) exclusively used conventional eating disorder diagnoses (bulimia nervosa and anorexia bulimia) and has concluded that eating disorder program outcomes are worse for individuals with diabetes. Similarly, Colton et al. (2015b) conducted a longitudinal study of one cohort to examine the prevalence, onset, remission, and recurrence of eating disorders in diabetic women and girls. The results showed that eating disorders in diabetic patients are persistent, with incidence remaining high even at the fourteen-year follow up (Colton et al., 2015b, p. 1216).

Here, as in the other examined research, Colton et al. (2015a/b) used the same criteria for diagnosing and treating conventional eating disorders in non-diabetic patients on patients with diabetes. Implicitly, then, researchers treat eating disorders as a comorbidity rather than a challenge arising from the specific conditions of living with diabetes. The researchers’ assumption that theory on conventional eating disorders is applicable to diabulimia, and that

eating disorders are comorbid to diabetes rather than a response to the stress of diabetes management, may inform the study results. If patients are being treated with the assumption that eating disorders are comorbid to their diabetes, then they may not receive treatment that adequately addresses how their diabetes may be at the root of their diabulimia. Therefore, diabetic patients being treated in the same program as non-diabetic patients may not receive appropriate care, which in turn may result in the poor outcomes reported by Colon et al. (2015a). Similarly, if the researchers fail to acknowledge the potential for a causal relationship between diabetes and disordered eating, then what they are describing as long-term persistence of eating disorders in diabetic women may in fact be a sustained failure of the healthcare system to provide patients with tools to cope with diabetes-specific psychosocial challenges.

T1 Diabetes and Psychosocial Challenges

Psychosocial challenges associated with diabetes have also been established in qualitative research. Jeong et al. (2018) conducted a qualitative study of 14 individuals ages 20-34 with T1 diabetes to investigate health-related stigma in young adults with T1 diabetes. Using transcripts from focus groups, Jeong et al. identified five themes impacting perceptions of stigma among the participants: (a) Desire to be Seen as a Person, Not a Disease; (b) Wanting to be “Normal”; (c) Feeling Ashamed Managing Diabetes in Public; (d) Struggling to Overcome Anger and Distress; and (e) Feeling Distrusted by Others to Manage Their Condition (Jeong et al., 2018, p. 44). The participants reported a “high degree of stigma in their daily lives, which negatively influenced...psychological well-being [and] led to...feelings of anger and distress” (Jeong et al., 2018, p. 44). Participants reported believing they were first seen as “diabetics” before being seen as people and feeling as though they could never behave like non-diabetic peers, which resulted in avoidance or delay of diabetes management. Two female participants, ages 20 and 23, admitted that they were “willing to

put themselves at risk” and not treat their hypoglycemia to avoid embarrassment in public or during school tests (Jeong et al., 2018, p. 47). One participant reported being shamed by her mother for using her insulin pump at a restaurant and was told to use it “in the bathroom away from other customers” (Jeong et al., 2018, p. 48). Some individuals who did not have the means to pay for insulin pump technology still used syringes. Due to common associations between syringes and drug use, one participant still using syringes to inject insulin felt compelled to perform the task in the bathroom to avoid harsh stares in public (Jeong et al., 2018, p. 48).

Some participants even reported that they did not drive, avoided recreational activities, and would not perform certain tasks at work, out of fear that a hypoglycemic episode might cause them to hurt another person in error (Jeong et al., 2018). Participants also expressed frustration, anger, and distress due to “stereotypical thinking on the part of acquaintances, friends, and family members (especially parents), and health care professionals” (Jeong et al., 2018, p. 48). Participants reported feeling unsupported, and perceived blame from others, such as “questions suggesting that the cause of their diabetes was poor diet” (Jeong et al., 2018, p. 48). Lack of knowledge about the distinction between T1 and T2 diabetes contributed to feelings of anger and frustration; comments such as, “but you’re not fat,” increased distress and stigma. The participants found it exhausting to explain their illness and the differences between T1 and T2 diabetes. Furthermore, when participants reacted with irritability to stereotypes and misconceptions about diabetes, others responded that “their emotional instability was caused by their unstable glucose” (Jeong et al., 2018, p. 48).

Finally, distrust and worry from family members regarding the individual’s ability to manage their diabetes resulted in feelings of anger and resentment (Jeong et al., 2018). My observation about such situations is that the patient is not only burdened with their own

condition, but also with the task of managing the expectations and emotions of concerned friends and family members. This is also true in situations where individuals feel exhausted from having to explain their illness to laypeople. Although the term ‘emotional labour’ is not used to describe this phenomenon, a person’s effort to explain their illness and manage the concerns of family is a good example of what emotional labour might mean for patients with diabetes. Although limited by its small sample size, Jeong et al. (2018) provided a valuable window into the struggles faced by young adults living with T1 diabetes. With its rich examples of lived experience, the study establishes an important foregrounding for further exploration into the concept of emotional labour, which may have viability in understanding these identified stigmas and struggles.

Diabetes Distress

As further evidence of the psychosocial challenges experienced by those living with T1 diabetes, researchers have sought to differentiate clinical depression and anxiety from distress that is specifically related to diabetes. One fruitful concept that has formed over the last decade is that of *diabetes distress*. Berry et al. (2015) define diabetes distress as: “...a rational emotional response to the threat of a life-changing illness. Distinct from depression, it is conceptually rooted in the demands of diabetes management and is a product of emotional adjustment” (p. 278).

Furthermore, the Clinical Practice Guidelines defines diabetes distress as: “...the despondency and emotional turmoil specifically related to the need for continual monitoring and treatment, persistent concerns about complications, and the potential erosion of personal and professional relationships” (Robinson et al., 2018, p. S130).

The turn away from the language of comorbidity is reflective of epistemological shifts in the researchers’ framework. The concept of diabetes distress represents an important shift in the medical paradigm; while mental health complications such as depression and anxiety

were commonly understood to be comorbid to diabetes (if implicitly related), this paradigm shift asserts them to be an outgrowth of diabetes, which reflects a better understanding of the patient's experiences and how patients are shaped by power dynamics inherent to social relations and institutional structures. The framework or lens of comorbidity may present a barrier to producing specifically tailored treatment for people with diabetes. As such, concepts like *diabetes distress* pave the way for better theoretical frameworks and subsequently better treatments.

Research on diabetes distress has proliferated (e.g., Carper et al., 2014; Hagger et al., 2016; Strandberg et al., 2014; Wardian & Sun, 2015; Winchester et al., 2016). Polonsky, Fisher, and their colleagues are known for the development of the Diabetes Distress Scale (DDS). Psychometric studies have shown the DDS to have “consistent, generalizable factor structure and good internal reliability and validity across four different clinical sites” (Polonsky et al., 2005, p. 626). The clinical and demographic characteristics of the four samples included a mean age was 56.3 years, and males comprised 52.3% of the total sample. The majority (83.3%) had type 2 diabetes, and the mean HbA_{1c} was 8.8%. In the three samples for which further demographic data were available, the majority of patients (50.4%) were using insulin: 42.5% were receiving oral hypoglycemic agents only, and 7.1% were managed by diet only. Non-Hispanic whites predominated (52.7%), followed by Asian Americans and Pacific Islanders (19.6%), African Americans (13.2%), and Hispanics (7.0%). Most subjects (87.7%) had graduated from high school (p. 628).

The DDS17 is as a 17-question screening instrument which asks patients to rate the degree of their distress on a six-point scale (Fisher et al., 2008). The Brief DDS screening tool (DDS2) is a 2-item screening instrument that has respondents rating these two statements on a 6-point scale pertaining to distress: (1) feeling overwhelmed by the demands of living

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with diabetes, (2) feeling that I am often failing with my diabetes regimen (Fisher et al., 2008, p. 246).

Fisher and Polonsky et al. (2012) have also found a “consistent pattern of curvilinear relationships between the DDS and HbA_{1c}” (Fisher et al., 2012, p. 259), a finding which demonstrates the correlation between diabetes distress and successful management. It can be speculated that young adults, who have seen their HbA_{1c} levels rise over the last decade, are also more likely to experience higher levels of diabetes distress. Although the DDS was developed using both T1 and Type 2 diabetes populations, the experience of *diabetes distress* is malleable and can apply to anyone managing their blood glucose on a daily basis and over a long period of time. For the complete DDS, please see Appendix A.

Conclusion

Despite these promising studies that demonstrate consistently the relationship between T1 diabetes management, psychosocial challenges, mental health challenges, and diabetes distress, what appears to be missing is language that describes the phenomenon occurring between diabetes management, its psychosocial challenges, and the resulting distress. Furthermore, understandings of diabetes and diabulimia appear to be lacking, with problematic assumptions about the applicability of eating disorder paradigms for the general population to diabetic populations.

The definition of diabetes distress provided by Berry et al. (2015) suggests that certain kinds of mental health challenges may be a natural outgrowth of the psychosocial challenges of T1 diabetes management. This is understandable, given the well-established correlation between diabetes management and diabetes distress, major depressive disorder, anxiety, and suicidal thoughts. Furthermore, diabetes distress sets an important precedent for how understandings of eating disorders and other psycho-social complications associated with diabetes can be understood. However, conceptually stronger explanatory language is

needed to fill in the gap between these events and better understand why the psychosocial challenges of T1 diabetes management lead to diabetes distress.

The concept of *emotional labour* may prove useful in elucidating the relationship between T1 diabetes management, psychosocial challenges, and resulting diabetes distress. More specifically, it may be the case that diabetes distress is the result of high amounts of emotional labour related to the psychosocial challenges of managing T1 diabetes. However, it is important to differentiate diabetes distress from emotional labour. Where emotional labour describes invisible aspects of diabetes management, such as investing energy into constant awareness, attention to details, and emotional processing, diabetes distress may result from being overwhelmed by the high demand of emotional labour to successfully manage the illness and its psychosocial challenges. Where diabetes distress is present, high emotional labour may also be present, but the two should not be conflated.

It is also important to distinguish between emotional labour and the concept of resilience, which may offer a tempting but inadequate explanation for why some people experience diabetes distress. Resilience describes an individual's capacity to cope with stress and adversity and may be a mediating factor between high emotional labour and diabetes distress. However, resilience should not be understood as the sole variable that may increase the risk of diabetes distress. Emotional labour, on the other hand, may be the invisible constant that links T1 diabetes management with diabetes distress.

A phenomenological approach is well-suited for studying emotional labour. Here, that phenomenon would be emotional labour related to diabetes management. This approach, while lacking the numerical data of quantitative studies, is productive in investigating and describing lived experience. Because emotional labour is experienced internally and may be difficult to communicate and measure quantitatively, a phenomenological study that employs in-depth interviews is best suited for exploring the inner lives of young adults with T1

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diabetes. In depth interviews can elucidate how participants experience living with diabetes, and how much energy they feel they are investing in the management of their disease.

Chapter 3. Theoretical Framework

Introduction

The earliest use of the term *emotional labour* can be traced back to sociologist Arlie Russell Hochschild's work, *The Managed Heart: The Commercialization of Feeling* (1983). However, here, I will be referring to the 2012 edition re-printed by Cambridge University Press. Citing the *Lucas Guide* (1980) magazine, Hochschild described the job performance testing at airlines as an anecdote for her explanation of the distinction between physical, mental, and *emotional labour*:

[Drinks were served] not only with a smile but with concerned enquiry such as, "Anything else I can get you, madam?" The atmosphere was that of a civilized party—with the passengers, in response, behaving like civilized guests...Once or twice our inspectors tested stewardesses by being deliberately exacting, but they were never roused, and at the end of the flight they lined up to say farewell with undiminished brightness (Lucas Guide, 1980, p. 66 from Hochschild, 2012, p. 6).

Hochschild describes the pushing of heavy metal carts through narrow aisles as physical labour, and the preparation and organization of emergency landings and evacuations as mental work. However, it is the "[suppression of] feeling in order to sustain the outward countenance that produces the proper state of mind in others" (Hochschild, 2012, p. 7) that she considers to be emotional labour. She goes on to say, "This kind of labour calls for a coordination of mind and feeling, and it sometimes draws on a source of self that we honor as deep and integral to our individuality" (p. 7). I wish to draw special attention to Hochschild's distinction between mental and *emotional labour*, as the two can be easily conflated. To be clear, *emotional labour* is not akin to concepts such as cognitive load (Sweller, 1988), which refers specifically to problem solving processes and is closer to what Hochschild calls *mental work*. Rather, emotional labour is "the management of feelings to create a publicly

observable facial and bodily display” (Hochschild, 2012, p. 7). Essentially, *emotional labour* places the needs of others (persons or social norms) above the needs of the person performing the emotional labour.

Since the publication of *The Managed Heart*, emotional labour has gained wide acceptance both in academic and public discourse. The concept has gained traction especially in discussions around gender and emotional and sexual relationships, specifically in the way “women direct attention away from their own needs and instead prioritize their partner’s needs, resulting in...problematic symptoms of gender inequality” (Fahs & Swank, 2021, p. ##). Goerisch and Swanson (2015) examined the American Girl Scouts and the way the organization “trains girls in the gendered practice of emotional labour” (p. 451). The researchers argue that “By learning to suppress or express certain feelings in public spaces in order to net more profit [on cookie sales], girls are socialized to not only regular their emotions, but also their bodies” (p. 451).

I would like to draw attention to public discourse around the term as well, since the proliferation of the concept among laypeople suggests resonance with everyday lived experience, and suggests that study participants may be familiar with the term. A 2015 Guardian article titled “Women are just better at this stuff: is emotional labour feminism’s next frontier?” Rose Hackman discusses the way “life has a layer of daily responsibility that is hardly discussed – one which falls disproportionately on women” (Hackman, 2015, subheading). Similarly, Melanie Hamlett’s 2019 article with *Harpers Bazaar*, “Men Have No Friends and Women Bear the Burden”, explores the ramifications of male socialization around friendship—namely, that female intimate partners typically come to play a multitude of conflicting roles in order to compensate for men’s unwillingness to process feelings via the appropriate channels. The article lists some of these roles in near-comic fashion: “friend, lover, career advisor, stylist, social secretary, emotional cheerleader, mom...on-call therapist

minus the \$200/hour fee” (Hamlett, 2019, para 3). Although the article does not explicitly define *emotional labour*, it treats the concept similarly to Hochschild’s original work by describing it as a kind of emotional management women do on behalf of their less willing male partners. It is notable here that the term has expanded and emphasizes not just managing one’s own emotions. Rather, *emotional labour* can be compounded by the demand to help manage others’ emotions as well. In this sense, the individual processes another’s emotions *for* and *with* them. The public discourse around the term is especially valuable, as it may make the concept more accessible to study participants moving forward.

In scholarly discourse, both the health and social sciences have employed *emotional labour* to explore a variety of topics. Birze et al. (2020) explored the role of gender in risk of health complications for emergency service communicators (911 call-takers and dispatchers) and found that “chronic forms of gendered workplace stress such as emotional labour...have associations with, and predict physiological responses to, acutely stressful events in the workplace” (p. 1). *Emotional labour*, which involves both *surface acting* and *deep acting*, was found to have some protective effects, but was also associated with physical and psychosomatic complaints. While *surface acting* involves feigning an appropriate emotion for the sake of public propriety, *deep acting* involves a genuine attempt to feel the “required emotion” (Mann & Cowburn, 2005, p. 154). Birze et al. (2020) speculated that there may be a “hidden cost” to the body that arises from *deep acting* (p. 8-9). Furthermore, Mann and Cowburn (2005) found that emotional labour was a featured prominently in mental healthcare workers’ daily work environments, and that “emotional labour was highly correlated with the high levels of stress experienced” (p. 161).

Kelly et al. (2019) employed the emotional labour triangle, adopted from Constanti and Gibbs (2004), to explore the experiences of sixteen Black women students at historically white-dominated post-secondary institutions. Using semi-structured interviews, Kelly et al.

(2019) explored the emotional labour Black women expended to mitigate “feeling as space invaders on their historically White undergraduate campus” (p. 1) and the emotional toll and stress experienced when proper coping mechanisms were not employed while expending emotional labour. When over-expended, emotional labour functioned as a “disengagement coping mechanism”, in which an individual disengages or distances themselves from the stressor (p. 3). Disengagement coping mechanisms are more common in people with marginalized identities, which can include race, gender, sexuality (p. 3), and, in the instance of my research, chronic illness. Kelly et al. (2019) noted that disengagement coping mechanisms are intended to maintain the comfort of hegemonic groups, which in turn has an isolating effect. Often, disengagement coping mechanisms are used out of fear of “feeding stereotypes or disrupting space” (p. 3). Although emotional labour holds the potential to serve as a more positive coping mechanism, in the case of marginalized identities, it may be “disproportionately expended to the detriment of Black women students,” especially because emotional labour is something that can be exploited (intentionally or unintentionally) by hegemonic groups (p. 8).

Emotional Labour and T1 Diabetes

Currently, there is no research that employs the concept of *emotional labour* to the qualitative study of living with diabetes. While the negative psychological and emotional effects of living with chronic illness are well documented, and researchers have taken important steps towards distinguishing these effects from conventional mental health diagnoses, the overwhelming majority of research is quantitative and does not employ concepts like *emotional labour*.

However, I propose that Kelly et al. (2019) offer insight into the viability of *emotional labour* to better understand the experiences of people with T1 diabetes. Kelly et al. (2019) used a similar approach to my own in employing semi-structured interviews to

explore participants' experiences with emotional labour and marginalization (albeit a different marginalization). The participants were college-aged, aligning them with the age demographic of my research. Yet what is key from Kelly et al. (2019) is the finding that *emotional labour* is disproportionately expended by marginalized people (p. 8), and that this over-expenditure has negative effects on the performer. Kelly et al. write:

The emotional energy Black women students expended trying to manage how White faculty and peers experienced them [emotional labour] negatively impacted their success in academic majors and left little room to explore their gendered-racial and other marginalized identities (e.g. class, sexual orientation) in spaces in which they were not performing. Emotional labour was a tool used by Black women to perform in roles acceptable in White and, in many cases, White male environments... (p. 8)

In a similar vein, one might propose a positive correlation between *emotional labour* and *diabetes distress*. People with diabetes live in a society that is founded on ableist, normative assumptions. For example, the assumption that all people can walk prevents city planners and architects from ensuring that spaces are accessible to those who cannot walk. Similarly, a person serving drinks may not understand the dangerous implications of replacing diet soda with regular soda for a person with diabetes. This is to say that people with disabilities and chronic illnesses must adapt and perform in a society that is not built for them.

However, because ableist assumptions are deeply internalized, normative, and therefore shared by the majority of people, disabled people who “don’t act normal” or respond negatively to marginalization may experience further stigma or hostility. As a result, people with disabilities and chronic illnesses must expend emotional labour not only to manage their own negative feelings about being marginalized, but the feelings of the hegemonic group that is complicit in that marginalization. As Jeong et al. (2018) has shown, people with diabetes experience social stigma precisely because public spaces are hostile

towards those who openly manage their illness with needles and medical devices, and this negatively impacts self-esteem and the ability to manage blood glucose.

Because people with diabetes are marginalized, they too may disproportionately expend *emotional labour* for the benefit of a hegemonic group—in this instance, able-bodied people. Furthermore, related to the research of Kelly et al. (2019), this in turn leaves people with diabetes little room to explore their own identities and their relationship with the complexities of chronic illness, which in turn may accrue hidden costs to mental health and one's ability, willingness, and energy to manage blood glucose.

Personal Reflection on my Emotional Labour and T1 Diabetes

I was diagnosed with T1 diabetes on December 7th, 2003. I was fifteen years old, an athlete, and the only daughter of high-strung, overbearing immigrant parents from former-Yugoslavia. It was the morning of my parents' wedding anniversary—four a.m. to be exact—when the phone rang and jolted me out of sleep. I thought it must be a wrong number from overseas, but minutes later, my mother was calling for me, a wobble in her voice.

“Oh God, oh God,” I heard her sobbing as I emerged from my room, still half-asleep. I didn't realize it at the time, but hearing the fear lace her voice like that left a mark on me. It's the first thing I remember whenever I think of that night. I'd had bloodwork done several days prior, and the lab was now calling, telling us to go to the ER. My father's response is dull in my recollection; I remember him being quiet as we got dressed and headed to the hospital. He'd been diagnosed with late-onset T1 diabetes five years prior—a diagnosis that echoed that of his father decades earlier. In hindsight, he'd been quiet because he knew what was coming. On some level, he felt it was his fault for passing on the faulty gene; he even admitted later that he worried my mother's family would blame him.

The ride to the hospital was quiet. I don't recall if I asked what the phone call was about. I knew it was about me and my bloodwork, but my parents were both acting

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devastated, and I didn't have the heart to ask them. This was the first time in my life with diabetes that I performed some degree of emotional labour for the sake of others. To protect my parents from bursting into tears, I put their needs before my own by staying quiet and having my questions unaddressed.

My time at the ER was a blur; I nearly passed out when the nurse stuck the IV in my hand, and after five hours in a hospital bed, I still didn't know what was wrong with me. Someone had finally told me my blood sugar was six times normal, but I had no idea what that meant. I just remember thinking, "They can fix it, right?"

Without being given a concrete answer, I was transferred to Sick Kids Hospital where I was formally diagnosed with T1 diabetes and put through a rigorous education on checking blood sugar, carb-counting, insulin-to-carb ratios, correction factors, dosing, exercise, diabetic ketoacidosis, treating hypoglycemia and hyperglycemia. I remained upbeat and cheery the entire time while my parents sulked and intermittently burst into tears as though I'd been handed a terminal diagnosis. At one point, they had to practice giving me a dose of insulin with an insulin pen. My mother kept refusing, saying she couldn't do it. She was horrified by the prospect of sticking a needle into her own child's flesh and had to be coaxed by the nurse educator and my assurances that it didn't hurt. That my own mother was repulsed by the act that I would have to perform multiple times a day, every day, for the rest of my life triggered a confusing cocktail of anger and hurt, but I clamped down on it, focusing on soothing her instead. My father kept lamenting that I didn't deserve this—that I'd been healthy, eating well, and exercising. In all of this, I had to be the calm and collected one, because if I wasn't, who would be? I didn't realize that I was expending emotional labour to keep everyone from falling apart more than they already were, and I was doing this at my own expense.

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I didn't realize it then, but my parents' reactions were like a tapeworm that'd snaked into my head, gnawing away at my sense of self. My self-image had been that of a strong, robust young woman with a future in sports. Who was this sickly girl with an IV and a hospital gown? I didn't recognize her, but she was what people saw when they looked at me. Was there really something so wrong with me that I would never again be healthy? *Did* I do something to deserve this? Was I going to die young?

Responses oscillated from sweeping assurances that I would be just fine—that I could have a totally normal life like anyone else—to my parents' catastrophic displays of grief. I compensated for my own insecurities and my parents' devastation by following instructions with military precision and demonstrating my ability to learn fast. I was smart, independent, and I wouldn't be anyone's burden. This also proved the fastest way to subdue my parents' fears. Within a month, my HbA_{1c} had dropped from 16% to 8%, shocking the entire medical team in the endocrinology department. After another month, my A_{1c} was 6.4%. I spent so much time consoling my family, helping them mourn, and performing normality that I left no space for myself to grieve or to process what I had lost. I'd over-expended emotional labour for the sake of others to quell the distress that arose from their ableist assumptions.

In the meantime, I adjusted to a new routine at school. The school did everything they could to accommodate my medical needs, and I put on airs about being fine—which at the time, I truly thought I was! I used crass humour to diffuse my peers' disgust with needles, joking that I “needed my insulin fix” and that I was “just shooting up like the cool kids.” I normalized necessary medical behaviour by riffing off of recreational drug use. This too was a form of emotional labour; rather than confronting what were unkind responses to my medical needs, I placed my peers' comfort over my mental health and over resisting casual ableism.

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Some kids' parents said I'd gotten diabetes because I ate too much sugar. Others refused to accommodate my dietary restrictions, saying I'd be fine if I ate a piece of cake. More than one person sent me an article purporting that okra could cure my diabetes. Wherever I turned, someone had a hot take. Medically uninformed opinions abound, I learned very quickly that responding in anger or frustration did little to change people's minds. In their view, they were simply well-intentioned, and I was overreacting, so I learned to smile, thank them for thinking of me, and delete whatever garbage they'd sent my way. When a boy rejected me because he didn't like needles and "just wanted to be with someone normal," I was angry and cut ties with him, but I also accepted this attitude as the norm and the expectation.

With my own family, I'd banned all conversation about cures or research breakthroughs. I couldn't tolerate hearing about them, because talks of cures had always been more for my parents than for me. *They* wanted a cure and *they* needed to maintain hope for one, but they framed it as something for me—something I should be excited about. Yet receiving these emails of 'diabetes news' did nothing but hurt me. I didn't want to hope for a cure, because it made coping with the present harder. This was *my* reality, and hoping for a better future only highlighted how unfortunate my present was. That my family was itching for a way out spoke volumes about how they regarded my diabetes. The fact that people made my diabetes about them felt selfish to me, yet there was no way to productively address this without mediation from a therapist. In the end, the onus of being self-aware, compassionate, patient, and understanding to people with normative assumptions fell on me, and I was tasked with expending the emotional labour to protect their feelings and their comfort at the expense of my mental health. This, in turn, resulted in five years of poorly controlled diabetes, during which I was too tired, too apathetic, and too self-loathing to be bothered.

In the end, however, I was responsible for my own mental health, and it was only through specialized therapy intended for those living with chronic illness that I was able to untangle

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all of the micro-traumas that had led me to a point of complete apathy and disregard for my own health. I was twenty-one years old at this point and had been living with diabetes for six years. What shocked me most about therapy was that 90% of our sessions revolved around my interpersonal relationships rather than my diabetes. Yet by gaining a stronger understanding of those interpersonal dynamics and finding tools to build healthier relationships and boundaries, my diabetes management organically improved. This has led me to believe that emotional labour is a key component of diabetes distress, and that poor blood glucose control does not necessarily result from gaps in technical know-how, but from destructive social dynamics and systemic marginalization of people with chronic illnesses, who in turn are required to disproportionately expend emotional labour to protect themselves from negative social and interpersonal outcomes. In a breakthrough moment several months into therapy, I told my doctor:

I feel like no matter what I do, I'm in for a life of misery. If I do what I'm supposed to do and manage my blood sugar, I have to live in a constant state of control and discipline, and that sounds like a terrible way to live. But if I do what I want and live how I want, I'll get complications and die young.

This was six years after my diagnosis, and it was the first time I was able to safely confront the illness on my own terms and express the core of my struggle honestly and openly, because I didn't have to manage someone else's feelings. In externalizing this sentiment, I finally grasped the extent to which I'd internalized the destructive messaging about diabetes, and the extent to which I'd exhausted my emotional resources navigating other people's baggage about chronic illness. The articulation of this hopelessness amidst a constant rally cry for hope from those around me was perhaps the most hopeful and emancipatory action I had been able to take in years. In speaking this truth, I had finally carved out a space for

myself, and ultimately, granted myself permission to allocate my emotional resources where they were most needed.

However, emotional labour is not something that simply ends when one untangles some of the complexities of interpersonal relationships, nor is it something expended solely for the benefit of others. Rather, it is a constant negotiation between an exhausted self and expectations that are both self-imposed and socially imposed. For example, dealing with feelings of failure or frustration when my blood glucose is erratic constitutes a form of emotional labour. Processing and working through anxiety prior to medical appointments, when I worry if there will be early signs of diabetes-related complications, is a form of emotional labour. The consequences for the choices I make with my body will always feel more severe because I have diabetes, and negotiating the competing impulse to both judge poor decisions and exercise self-compassion requires emotional labour.

I recall a specific instance in which the consequences for my choices felt particularly salient to me. About five years ago, I was given a Nintendo Switch for Christmas. As an avid gamer, I wanted nothing more than to spend winter break in my living room, playing video games until four a.m. and eating nothing but pizza and red velvet cupcakes. For a person without diabetes, a week of poor sleep and diet would feel relatively inconsequential in the grand scheme of things, and they would certainly not be judged too harshly by peers or healthcare professionals. However, such behaviour for someone with diabetes is potentially laden with guilt, shame, and externally, judgment from concerned peers, family, and less compassionate healthcare professionals. In other words, potential consequences change the metric for good or reasonable behaviour, and negotiating the imposition of that stricter metric, its enforcement by external parties, and the implicit value judgments around failing to measure up—all while trying to maintain a positive self-concept—requires an enormous expenditure of emotional labour.

Chapter 4. Methodology and Research Design

Introduction

The aforementioned association between diabetes and mental health issues has become so ingrained in health sciences literature that it is taken as self-evident, with little attention given to the ‘why’ and ‘how’ of the assumed association. In Latour’s critical theory on science, this process is known as *black boxing*:

...the way scientific and technical work is made invisible by its own success. When a machine runs efficiently, when a matter of fact is settled, one need focus only on its inputs and outputs and not on its internal complexity. Thus, paradoxically, the more science and technology succeed, the more opaque and obscure they become. (1999, p. 304).

Unfortunately, the health sciences are not immune to this. Health researchers seems less interested in the qualitative experience of the people who live with psychosocial challenges spurred by diabetes because the connections have become assumed. This is reflected in my literature review, which yielded only a single qualitative study examining the experience of social stigma in young adults with T1 diabetes (Jeong et al., 2018).

For these reasons, phenomenological research was an appropriate methodology for this thesis research. The goal of my research was to add theoretical complexity to a T1 diabetes/mental health association that has become assumed for both researchers and healthcare professionals alike. Neubauer et al. (2019) argue that, “The questions that phenomenology can answer, and the insights this kind of research can provide, are of foundational importance to health professions education (HPE) scholars” (p. 91). In the same spirit, I wanted to contribute to a nuanced and indepth understanding of the experience of living with T1 diabetes and its accompanying psycho-social challenges.

Interpretive Methodology

This research ascribed to the tenants of hermeneutic phenomenology. Phenomenology is defined as a discipline that

seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it. The goal of phenomenology is to describe the meaning of this experience—both in terms of *what* was experienced and *how* it was experienced. (Neubauer et al., 2019, p. 91)

They go on to argue that, “By examining an experience as it is subjectively lived, new meanings and appreciations can be developed to inform, or even re-orient, how we understand that experience” (p. 92). However, there are different types of phenomenology that have arisen from various philosophical traditions, and those traditions in turn have informed methodologies founded on each respective tradition’s assumptions. I employed Interpretative Phenomenological Analysis (IPA) (Smith, 2015; Smith et al., 2009) and the philosophical assumptions of one of its philosophical parents, hermeneutic phenomenology. I used the term hermeneutic phenomenology to describe the philosophical-intellectual movement and philosophical assumptions adopted when employing IPA. Where hermeneutic phenomenology is a philosophical-intellectual umbrella term, IPA informs a specific approach to data analysis that partly originates from hermeneutic phenomenology.

Hermeneutic Phenomenology

Hermeneutic phenomenology is rooted in the philosophy of Heidegger and Gadamer. Broadly speaking, all phenomenology is united by a concern with “the life world” or human experience as it is lived, emphasizing details that are commonly seen as trivial or taken for granted. The goal of all phenomenology is to create meaning and understanding (Lavery, 2003). However, where hermeneutic phenomenology departs from its predecessors via Heidegger is through the concept of ‘Dasein’ from his 1927 work, *Time and Being* (Kakkori,

2009, p. 24). ‘Dasein’ can be roughly translated as “the situated meaning of a human in the world” (Lavery, 2003, p. 24). Husserl, the father of transcendental phenomenology, understood humans as the “knowers” of the world, but Heidegger understood humans and the very idea of “knowing” or “consciousness” as being inseparable from the world. Furthermore, this consciousness is informed by lived experience, and therefore, understanding does not constitute a way of “knowing,” but rather, a way of “being” (Lavery, 2003, p. 24). Heidegger emphasized the historicity inherent to ‘understanding’—that is, one’s background or positionality. Lavery writes that:

Historicity, a person’s history or background, includes what a culture gives a person from birth and is handed down, presenting ways of understanding the world. Through this understanding, one determines what is ‘real’, yet Heidegger also believed that one’s background cannot be made completely explicit. (2003, p. 24)

Gadamer, the second canonical figure in hermeneutic phenomenology, built on Heidegger’s notion that “language and understanding are inseparable structural aspects of human ‘being-in-the-world’” (Lavery, 2003, p. 25). Emphasizing the role of language in interpretation, Gadamer argued that understanding and hermeneutics were married through language, and that interpretation was not a fixed process, but a fluid and evolving one. Interpretation, then, is never definitive, and Gadamer was adamant that scientific method, despite claims to objectivity, could never truly be free of values, assumptions, and biases (Lavery, 2003). Echoing my own sentiments as a researcher, Gadamer understood Husserl’s notion of bracketing subjectivity as being impossible, as one can never excise themselves from their context.

The key ontological assumption of hermeneutic ontology, then, is that lived experience is an interpretive process, and this interpretation is always situated in the individual’s context. Furthermore, the epistemological assumption of hermeneutic

phenomenology is that the observer (or researcher) is a part of the world and therefore cannot be bias free (Neubauer et al., 2019). As such, there is no possible way to bracket one's subjectivity as transcendental phenomenology suggests. Hermeneutic phenomenology does not ascribe to any objective, universal truths where the study of experience is concerned; rather, truth is always situated, and there is no vacuum into which the researcher can retreat to better understand phenomenon. The researcher's positionality will always influence data analysis, as the interpretive process is one of navigating the relationship the researcher has with their reality, with themselves, and with their participants.

In this regard, hermeneutic phenomenology can be understood as post-positivist in that it does not understand reality as something 'out there,' with immutable laws and objective truths waiting to be discovered. Rather, there is no one, set reality, but "multiple realities that are constructed and can be altered by the knower" (Lavery, 2003, p. 26). Reality, and knowledge about reality, are therefore not 'out there', but something constructed from the situated perspective of the knower.

Practical and Theoretical Implications

In considering the differences between Husserl's transcendental phenomenology and Heidegger's hermeneutic phenomenology, it may be productive to consider the way epistemology and ontology interact, and how particular facets of existence are coded as either epistemological or ontological. For example, Lavery (2003) notes that Husserl was more focused on "the epistemological question of the relationship between the knower and the object of study" (p. 27). This is echoed by Neubauer et al. (2019), who assert that Husserl "was interested in the nature of knowledge (i.e., an epistemological focus), [and] Heidegger was interested in the nature of being... (i.e., an ontological focus)" (p. 94). Inherent to Husserl's focus is the assumption of a singular ontology, and ascription to a singular ontology renders it meaningless to question ontology itself. Thus, people whose experience differs

from a hegemonic expectation may find those experiences being relegated to a discourse on epistemology, because the ontology is taken as self-evident. This can create a hierarchy of knowledge, where epistemologies that align with the assumed ontology are privileged as normative because they ascribe to a hegemonic understanding of reality.

For this reason, research that focuses on the lived experiences of a specific demographic may be better served by hermeneutic phenomenology, which takes seriously the possibility of multiple ontological truths. This in turn subverts the tendency to establish hierarchical knowledge, as it demands an acceptance of fundamentally irreconcilable realities that are constructed through context. By deferring to hermeneutics and to the notion of ‘understanding as being’ rather than ‘understanding as knowing,’ researchers are given more space to avoid the trappings of positivism and hegemonic knowledge production.

Interpretive Phenomenological Analysis

While remaining loyal to the philosophical underpinnings of hermeneutic phenomenology, I used Interpretive Phenomenological Analysis (IPA) to generate and analyze data. IPA was developed as a psychology-focused research approach by British psychologist Jonathan Smith and has gained popularity in clinical and counseling psychology, as well as in social and educational psychology. The goal of IPA is to explore how people make sense of their personal and social world, and to make meaning of experiences, events, and states (Smith et al., 2015). Furthermore, Smith et al. (2015) reaffirm that the core of IPA is an interpretative research approach, aligning itself well with the hermeneutic tradition. Like hermeneutic phenomenology, IPA is designed to be participant-oriented as it concerns itself with the meanings people ascribe to their experiences (Alase, 2017).

Echoing hermeneutic phenomenology, IPA “assumes a chain of connection” between a person’s cognitive, linguistic, affective, and physical state of being (Smith et al., 2015, p.

54). Although IPA has commonalities with both clinical and social psychology theory, specifically in its concern for mental processes, IPA differs from these mainstream disciplines in its approach to studying how people think about their own experiences, while clinical psychology relies heavily on quantitative rather than qualitative research. Furthermore, IPA appears to reject the behaviourist paradigm that has dominated much of cognitive psychology since the 1950s (Smith et al, 2015, p. 54). For these reasons, IPA was well-suited for exploring the experiences of people with T1 diabetes, who may understand their lived reality quite differently from non-chronically ill people.

In endeavoring to better understand the experience of young adults living with T1 diabetes in relation to the phenomenon of emotional labour, and its accompanying psycho-social issues, IPA proved to be a suitable interpretive methodology. Considering the ‘black boxing’ of the assumed association between T1 diabetes and psycho-social challenges, IPA was also fruitful in demystifying some of the quantitative literature that has been taken for granted.

Research Design

Participants

I recruited 9 participants between the ages of 18 and 30 who were diagnosed with T1 diabetes by a licensed physician and had been living with the illness for a minimum of two years. The mean age of participants was 25.6, the mean duration of tT1 diabetes was 13.9 years, and the mean age at diagnosis was 11.9 years old. Given potential barriers and additional ethical considerations around recruiting minors, the study focused on young adults who were old enough to give consent for themselves. Furthermore, because the first year following diagnosis can be particularly tumultuous as patients adjust and learn the idiosyncrasies of their illness, I aimed to recruit participants who were more likely to have

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‘settled’ into life with diabetes. For this reason, the two-year since diagnosis of diabetes inclusion criterion.

Sampling

Participants were recruited through the social media platform Twitter, and through the T1 diabetes research database, ConnecT1D. Furthermore, the Juvenile Diabetes Research Fund (JDRF) advertised the study, and several individuals affiliated with the JDRF contacted the researcher to participate. Because these communities are often openly engaged with and committed to improving broader understandings of chronic illness, social media provided a fruitful avenue to recruit participants who were genuinely enthusiastic about the study.

Social media ‘etiquette’ was employed during Twitter recruitment. The researcher placed an open call for participants on Twitter, using appropriate hashtags such as #Type1, #T1, #T1D, and #LiveBeyond, which are frequently used by people with T1 diabetes and advocacy groups such as Beyond T1 and the JDRF. Athabasca University’s recruitment poster template was used in the open call (See Appendix B). Second, the researcher approached specific advocacy groups’ social media accounts via private message to facilitate broader dissemination of the open call. Third, if the researcher was aware of mutual social media followers who live with T1 diabetes, these individuals were approached through Twitter’s private messaging system to gauge interest in the study. If the individual expressed interest in the research, I sent a formal invitation via email. This invitation followed Athabasca University’s invitation to participate template (See Appendix B).

Ethical Considerations

I completed the Tri-Council Policy Statement: Course on Research Ethics (TCPS-2: CORE) in 2019 (see Appendix D) and obtained ethical approval for this research from Athabasca University’s ethics board [File No. 24238].

Information Letter and Informed Consent

All participants were provided with the information letter and informed consent form, which include detailed information about the researcher, the purpose of the research, the type of research being undertaken, the reason for the specific participant's selection, and the procedures for the research (in this instance, explaining semi-structured interviews and their expected duration) (Appendix B).

Furthermore, the consent form indicated that participation was entirely voluntarily, and that the participant had the right to refuse or withdraw from the study at any time. The participants were also informed about the risks and benefits of the research and how their confidentiality would be maintained. The consent form indicated that the research results would be shared with participants, and that the results would be shared more broadly via publications and conferences. Finally, the consent form contained contact information should the participant wish to communicate any questions or concerns with me, the researcher, my thesis supervisors, and/or AU's Research Ethics Office. Participants were provided an opportunity to ask questions and seek clarification on any points of interest.

Data Collection

Semi-structured interviews are the favoured method of data collection in IPA. In this method, the researcher has a set of open-ended questions, but the interview is ultimately participant-oriented and only guided by the interview questions (Alase, 2017). Question order is not as important as engagement, and the researcher is encouraged to delve deeper into areas of interest that arise organically during the interview process. Furthermore, the researcher can engage the participant's areas of concern if the participant appears more inclined towards a specific line of discussion (Smith et al., 2015). One strategy is to allow the participant to speak about a topic with as little prompting as possible to avoid leading questions. Smith et al. (2015) note that 'gentle nudges' are better than explicit questions and

emphasize that this runs counter to most other methodologies in psychology. Therefore, it is important to draft questions several times, as the first draft may prove too explicit or leading (Smith et al., 2015).

Another interview technique is ‘funneling’, which can be appropriate when there is an interest in both the participant’s general views and more specific views on a topic. The first question attempts to extrapolate the participant’s general view on the topic, and subsequent questions probe more deeply into specific topics once this general view is established. It is important to begin with the general and move to the specific, as the opposite sequence can lead to responses that confirm the researcher’s own bias (Smith et al., 2015, p. 62). These techniques were considered in the data collection process, though they occasionally shifted based on the participant’s communication style. Regardless, a semi-structured interview was employed (Appendix E), and the researcher sought to maintain a casual and conversational tone throughout the interview.

All interviews were conducted online via Zoom. Given the move towards web-based research interviews even prior to COVID 19 (Gray et al., 2020) this approach afforded a larger geographical area for recruitment. The call was password protected, and only the interviewer and the participant were allowed into the call. The call was recorded with the participant’s consent, and recorded files were stored on password protected AU’s Office 365. Interviews were then transcribed onto .docx files for analysis and interpretation, and these files were likewise securely stored on AU’s Office 365. Participants were assigned aliases during the research write-up to protect their identity. All data is archived on AU’s Office 365 unless otherwise specified by the participant.

Data Analysis

Smith et al. (2015) emphasize that there is no prescriptive way of analyzing data in IPA, though there are several suggestions to ensure scholarly rigour. They recommend that

interview transcripts be read several times over, with notes taken on one side of the margins about interesting aspects of the interview. They then recommend re-reading the transcript using the other margin to note emerging themes. Concise phrases are used to encapsulate the essential quality of what was found in these initial notes (Smith et al., 2015).

Alase (2017) recommends that the first read can be used to take note of common themes, such as words or phrases that are repeated in the participant's responses. Following this, it is recommended that the researcher re-read the transcript two more times for clarity, which allows them to adjust themes. Alase notes that the process is laborious, time-consuming, and demanding of both imagination and emotional energy; the researcher's goal is not only to absorb what the participant was saying, but to also better understand the participant's state of mind and any implied meaning through what may have been omitted or said a particular way. Alase proposes three cycles of condensation, where longer phrases and statements are gradually distilled to essential phrases or words (one or two words long) that capture the "core essence of the central meaning of the research participants' lived experiences" (p. 16).

Alase (2017) notes that researchers are encouraged to bracket themselves from the lived experience of the participants; this aspect of IPA appears to closer align with transcendental phenomenology. Researchers are encouraged to describe their own experience with the studied phenomenon to avoid inserting that experience into the participants' narratives. Furthermore, researchers should develop a list of significant statements "as a foundation to understanding the phenomenon" (Alase, 2017, p. 16). These statements should be treated as having equal worth, and they may be drawn directly from interviews. Significant statements are then grouped into larger themes. These themes s accomplish two things: first, they describe 'what' the participants experienced. This is known as a textual

description. Second, the researcher articulates the ‘how’ of that experience, and this is known as a structural description (Alase, 2017).

These recommendations were followed during the data analysis stage of research. Furthermore, I employed my own background in discourse analysis from the humanities to give greater depth to the analysis.

From Humanities to Health Sciences

As a researcher originally trained in the humanities, transitioning into health sciences research methodologies took considerable adjustment. In the humanities, my methodologies are strongly rooted in discourse analysis—an approach I incorporated throughout my literature review. Discourse analysis was a useful tool that I employed in conjunction with IPA—albeit unconsciously—to assist me in unpacking and interpreting my interviews with participants. It has also been vital to my own self-reflexivity, as my own thoughts, perspectives, and words are certainly not above analysis. Nonetheless, I was required to expand my analytic tool kit to align better with the techniques of IPA. In preparation for my thesis research, I enrolled in a required course on advanced qualitative research methods. The course incorporated four informative and useful assignments: a reflexive journaling assignment that allowed me to explore my own assumptions, concerns, and research process; a research report that required student researchers to peruse media reporting on a public health concern and practice coding; a detailed analysis of a research methodology of our choice; and finally, a report on our experiences working with NVivo, a software that assists researchers with organizing and coding their data in one place.

Of all the skills learned and practiced, I found coding to be the most challenging, as it constituted a method of presenting information that I frequently found counterintuitive after years of training in the humanities. In our media report coding assignment, I was able to

practice coding, which also provided me the opportunity to unpack my own analytic process and become more conscientious of a process I took for granted as intuitive.

Transcription

Initially, I intended to transcribe the interviews myself. I reasoned that this would give me the opportunity to make my own decisions about transcription. This decision was initially informed by my own humanities training, which has taught me that when content is transposed from one medium to another, it is fundamentally changed. My doctorate dissertation's first chapter explores the impact of recording oral folklore to the written medium—an act that scholars agree constitutes a form of translation. Likewise, transcribing audio files is also an act of translation. So much is communicated through tone, cadence, pauses or lack thereof, and I wished to transcribe these nuances as faithfully as possible. Furthermore, editing for mechanical correctness creates an additional barrier, as the additional elements such as punctuation can impact how a statement is perceived. However, I learned quickly that transcription is incredibly time consuming and was forced to re-evaluate my own capacity. After deciding that I was not equipped to transcribe nine interviews that ranged from one to two hours, I hired a transcriptionist and provided her with instructions to include pauses and colloquialisms. For example, pauses during which the participant appeared to be thinking about their response were indicated in parentheses. I also included a list of “key terms” that were diabetes specific, such as CGM, T-Slim, HbA_{1c}, Omnipod, Libre, Dexcom, diabulimia, to help orient the transcriptionist.

After receiving the transcriptions, I read them while listening to the original audio files, penciling in any discrepancies, clarifying inaudible phrases, or adding punctuation to modify how a sentence might be read or perceived so that it would better align with the emotion or sentiment expressed verbally. This allowed me to highlight parts of the interview that I thought deserved more attention or came across to me differently in writing than in

audio format. While I did not clip the audio files, which involves cutting out small excerpts of the audio recording for coding purposes, my transcriptions contained time stamps, making it simple to return to the appropriate place in the original audio recording. I preferred this method over clipping, as it allowed me to listen to the surrounding audio content to re-contextualize the comments of interest.

Writing Emotion

Perhaps importantly, my work in fiction writing has given me a background in communicating emotion through writing. Fiction as a genre must abide by the mechanical rules of written language, but its portrayal of human emotions and experiences must be believable. The creative use of punctuation, dialogue tags, and action beats, for example, allows fiction writers to convey a character's emotions believably while honouring editorial standards for mechanical writing. Consider the following two framings of the same dialogue:

“I don’t know what you want from me,” she said.

She sighed. “I don’t know what you want from me...”

While the first example will come across as clipped and defensive to a reader, the second will come across as defeated and uncertain. The placement of the action-beat in the second example sets an emotional tone—one of resignation—before the dialogue even happens, and the ellipses punctuating the dialogue creates a sense of uncertainty by implying that the speaker is trailing off, considering how to follow up. Thus, two small adjustments to the writing can dramatically impact not only what emotion is conveyed, but the personality and temperament of the character. This is something I was mindful of when initially reading through my transcriptions, and it was one of the reasons I wished to read them in tandem with listening to the audio recordings.

While transcription is not fiction writing, some of the broadly accepted techniques of fiction writing give clues to how transcriptions might be perceived or interpreted by a reader.

When editing the completed transcriptions, I was able to apply my skills as a fiction writer to ensure that if a participant spoke with a particular affect, I could reasonably convey that affect in writing to preserve the participant's emotional reality to the best of my ability. For example, I incorporated specific punctuation to convey pauses, and I indicated tone or specific actions taken by the participant in parentheses (i.e., sighing, tearing up, mumbling). Of course, this too is an act of translation and interpretation, but I strongly believed that the attempt to make emotions legible through writing are preferable to potentially eliminating or minimizing them.

Sorting Things Out

Coding constituted the most challenging aspect of the research process, as it required me to think about data differently than I normally do. As a researcher of historiography and literature, my impulse was to create narratives from data, based on my philosophical belief that all knowledge production is narrative. Even the act of coding, I believe, is an act of producing narrative, as it requires the researcher to make assumptions about what they are perceiving from participants and to ascribe language and meaning to those perceptions. For example, when two or more participants described a similar experience, I had to make a decision about whether these experiences ought to be homogenized for the purpose of coding. While common themes clearly emerged, I was nonetheless tasked with assigning and naming those themes. This rendered me an active producer of the themes I ostensibly identify. Thus, coding is not merely an act of identifying an objective fact that is present across the interview content; rather, codes are constituted both by the participants' words and the researcher's choices.

Being mindful of this, I began my coding with broader themes that could be narrowed into subthemes at a later point. For example, I started with the very premise of my project—emotional labour—and highlighted instances where the participants used the phrase while

describing their experiences. This allowed me to pare down some of the content and focus on the associations that participants were making with emotional labour. I wanted to ensure that I limited homogenization as much as possible, especially in the early phrases of data analysis.

I double-spaced every interview transcription to facilitate notetaking and printed the interviews so that I could read them off the page with pencil and highlighter in hand. While I had some experience with NVivo, I found the affective experience of reading and taking notes by hand to be more productive. I read the interviews first without taking any detailed notes to give myself some big-picture familiarity with the content. While doing this, I jotted down broad themes or phrases that came up in identical language, for example, “bad diabetic,” “family,” “romantic partner,” “education,” “healthcare,” “disability,” “negative emotions.” Each of these words was assigned a highlighter colour, and on my second read through, I began highlighting instances of these broader themes.

Once I had made highlights, I re-read the interviews and wrote out sub-themes that emerged under each of these broader themes, including the context for the theme. It was important to me to understand what circumstances were giving rise to specific associations for participants. For example, was the phrase “bad diabetic” used in conversations about family or doctors? Was there a connection between dynamics in healthcare settings and certain negative emotions? I wrote these notes in point form, jotting down page numbers and copying/pasting quotes that were particularly poignant or representative. At this point, I was able to consolidate or eliminate certain subthemes as I began to re-organize my remaining notes, copying and pasting content into new themes, which grew increasingly specific. Once this process was complete, I began composing my results in long form.

Limitations

My personal relationship to the illness, T1 diabetes and my own lived experiences informed the assumptions I brought into the study. As such, careful consideration of

positionality and reflexive journaling was employed to minimize the researcher's unconscious 'insertion' of personal opinions and judgments. This does not mean that the researcher's analysis was free of subjectivity, but rather, that the researcher was careful not to override the thoughts, opinions, reflections, and insights of the participants. Thus, the researcher's perspective is presented alongside the participants' statements. Rather than seeking total elimination of bias, the researcher aimed for awareness of bias and its impact on data analysis. It is critical to emphasize that the researcher's background as a T1 diabetic in combination with the researcher's training in critical theory and discourse analysis informs the very premise of the research. Therefore, the intrinsic connection between the researcher's experience and the research demands transparency around bias rather than its total elimination.

Third, the COVID19 pandemic may have had a significant impact on participants' lived experience, however this provided a fruitful opportunity to study emotional labour in chronically ill populations, given the specific challenges the pandemic presented to those who are required to continually manage their condition, regardless of external circumstances.

Fourth, discussing sensitive topics such as one's experiences living with T1 diabetes may cause some participants to experience emotional or psychological distress. To mitigate this, it was made clear to participants in consent forms, at the beginning of the interview, and throughout the interview process that they are not obligated to answer every or any questions. The interviewer strove to be personable and minimize any impressions of authority, as there is often an inherent power dynamic to the researcher-participant relationship. The interviewer worked to recognize this power dynamic and practice self-reflexivity during the interviews to ensure that participants felt comfortable. If distress arose, the participant could discontinue the interview and withdraw their participation, however, no such instances occurred.

Finally, with all online communication, anonymity and privacy are a prime concern, especially when interviews are recorded. The video call application's safety features were evaluated and used in full to ensure that risks were mitigated, and to ensure that the participant's privacy was protected. As previously mentioned, the call was recorded with the participant's consent, and files were stored on AU's Office 365, which is password protected. Participants were assigned aliases during the research write-up to protect their identity, and file names use these aliases as well. All data is archived AU's Office 365 unless otherwise specified by the participant.

Reflexivity and Rigour

To maintain reflexivity, the researcher strove to maintain awareness of her experience living with diabetes, as well as awareness of her own positionality, particularly the ways in which she may benefit from systemic privilege. The researcher maintained awareness by externalizing her thoughts, feelings, questions, doubts, and potential conflicts through reflexive journaling. Orange (2016) has noted that “the continual critical process of self-evaluation allows researchers to consider the influence their positionality plays in their research” (p. 2176). Furthermore, Ortlipp (2008), has concluded that reflexive journaling allows researchers to make their “experiences, opinions, thoughts, and feelings visible and acknowledge part of research design, data generation, analysis, and interpretation” (p. 703). However, it is Saldana (2019) who most poignantly summarizes the spirit of self-reflexivity in qualitative research, and it is this particular iteration that the researched strived for:

...being a qualitative researcher means **knowing and understanding yourself**—
knowing and understanding yourself so deeply that it scares the hell out of you. You are your own case study, a mirrored perception of self that is reflective, reflexive, and refractive about your age, your gender, your ethnicity, your sexual orientation, and all the myriad of ways you categorize and construct your personal identities. It's dwelling

deeply in your own presence, knowing where you are in place and positionality, in space and standpoint, in context and in contrast (p. 2044).

In keeping with the principles expressed in Saldana (2019), I began my reflexive journaling process in early 2020, exploring why I had chosen this avenue of research, as well as how my own epistemological and ontological frameworks may impact my relationship to and understand of others' narratives of living with diabetes. Reflexive journaling continuous throughout 2021, particularly between interviews and during the coding process. I have included samples of these journals in Appendix C.

Summary and Significance

There is evidence that T1 diabetes is linked with increased psychosocial challenges that impact mental health and health regime adherence (Robinson et al., 2018). Clinical depression, anxiety, eating disorders, social stigmatization, and 'diabetes distress' are common and well-recognized repercussions of these psychosocial challenges and long-term diabetes management, especially in young adults (Berry et al., 2015; Colton., 2015; Ferro, 2016; Jeong et al., 2018). The literature to now has focused strictly on the association between T1 diabetes and mental illness, T1 diabetes and psychosocial challenges, and has suggested new ways of understanding distress particular to T1 diabetes (Fisher & Polonsky, 2005-15). However, research has yet to name what it is about psychosocial challenges that instigates such high occurrences of distress in young adults with T1 diabetes.

Therefore, this research sought to explore the following questions: Do young adults with T1 diabetes experience high levels of emotional labour? Can the concepts of emotional labour be used to deepen understandings of why young adults with T1 diabetes experience increased risk of psychosocial challenges? To explore these questions, the researcher conducted semi-structured interviews with a small sample of nine participants and used Interpretative Phenomenological Analysis.

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This research is significant in that it can contribute to an evolving framework of understanding the high incidence of psycho-social challenges and diabetes distress experienced by people living with T1 diabetes. Furthermore, while most studies on diabetes and psychosocial challenges are quantitative and aim to establish correlation, there is little qualitative research exploring the *how* and *why* of phenomena. The aim of this research was to address that gap with articulation of the experience of living with diabetes in relation to the phenomenon of emotional labour. Lastly, this research is both significant and novel in that it incorporates diverse approaches, theory, and knowledge from the humanities, the health sciences, and the researcher's lived experience with T1 diabetes.

Chapter 5. Results

Introduction

Through this research, I sought to establish whether young adults with T1 diabetes experience high levels of emotional labour and whether the phenomenon of emotional labour would deepen understandings of living with T1 diabetes. Thus, understanding if the phenomenon of *emotional labour* resonated with participants was an important facet of the interview process. However, during my research, it became evident that for the participants I interviewed, emotional labour was already assumed to be an inherent part of living with diabetes. That is to say that none of the participants disputed that diabetes requires a high degree of emotional labour, and they unanimously treated it as a given reality. In fact, most of the participants sought out the study precisely because the title “T1 Diabetes and Emotional Labour” signaled to them an opportunity to speak about their experience with chronic illness and emotional labour. Importantly, participants readily adopted the phrase *emotional labour* during the interviews to name and describe some of the more complicated social, interpersonal, and intrapersonal dynamics of living with diabetes.

In recognizing that participants have highly individual and valuable lived experience that arises from the socio-cultural intersections they occupy, I initially dedicated space to each individual participant so that important insights that might otherwise be lost in the extrapolation of data would have their place. However, due to the material constraints of this project, such a narrative analysis was not possible. Therefore, as per IPA, I analyzed each interview for themes and then further analyzed the data for common themes across interviews. I then identified key themes that characterized the major sources of emotional labour for the participants. I endeavoured to reflect the unique experiences of each participant within the themes, which offer evidence that people with diabetes experience emotional labour. As I present the participants’ examples and narratives, I provide analysis of how and

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why this emotional labour is experienced. My goal with this analysis was two-fold: First, to amplify the participants' voices, and second, to deconstruct the "mechanics" of how and why particular experiences might come to constitute emotional labour for the participants. Thus, the analysis is not a presentation of unequivocal fact but one of interpreted perspective truth.

All participants were woman-identifying and most specified that they were White (7/9). Most were Canadian (7/9). They ranged in age from 23-29 and had T1 diabetes for 5-22 years; the youngest age of diagnosis was 2 years of age, and one participant was diagnosed in early adulthood (see Table 1).

Table 1

Demographic Information (N=9)

Characteristics	N (%)
Gender	
Woman-identifying	7 (78%)
Man-identifying	0
Race	
European White	7 (78%)
Black	0
Asian	0
Near and Middle Eastern	1 (11%)
Mixed Race	1 (11%)
Nationality	
Canadian	7 (78%)
American	2 (22%)
	Mean (Range)
Ages (years)	25.6 (23-29)
Diabetes Duration (years)	13.9 (5-22)
Age at Diagnosis (years)	11.9 (2-23)

Participant Familiarity With Emotional Labour

Although associations and definitions varied somewhat from participant to participant, there was consensus that *emotional labour*, in the context of diabetes, referred to

the invisible burdens of chronic illness management. Furthermore, most of the participants were aware of the term's usage in popular discourse, specifically in the context of romantic partnerships and domestic labour. Central to many participants' understandings of where they felt required to expend emotional labour related to feeling obligated to perform a particular way for the comfort of hegemonic groups, which aligns well with Kelly et al. (2019).

A shared thread among all the participants is that they understood *emotional labour* to be tied to their marginalization as people living with chronic illness. All participants understood emotional labour as something obligatory and, indeed, laborious or burdensome. For individual participant definitions of emotional labour, see Appendix F.

As I now present the identified themes it is important to note that they are not meant as discrete, separable categories of issues faced by people with diabetes. Rather, the categories highlight noticeable commonalities that emerged and weave together to form my interpretation of the participants' interpretations of what was navigated and managed through the expenditure of emotional labour. Thus, there is overlap and interconnectedness between and across themes. The themes are as follows: tough love and interpersonal relationships, the need for mental calculus, managing misconceptions from laypeople, systemic barriers, managing misconceptions in healthcare settings, the intrapersonal relationship to diabetes, and finally, the "bad diabetic" and an internalized expectation of perfect control.

Theme 1: Tough Love and Interpersonal Relationships

Five out of nine participants reported experiencing "tough love" from family, friends, and medical professionals, which caused them to expend emotional labour. They recounted that others' rigid demands for ideal glycemic control created friction, eroded trust, and rendered the participants' interpersonal and medical spheres combative rather than supportive. These dynamics created a demand for the participants' emotional labour, as they often took on responsibility for managing others' feelings, diffusing conflicts, and setting

boundaries. Thus, participants had to develop coping mechanisms (both positive and negative) as those around them were unequipped or unwilling to do so. Participants did not find tough love motivating, and responded by faking results in their logbooks, which compounded feelings of loneliness, isolation, guilt, and shame. The “diabetes police” was inevitably encountered and had to be managed.

A. The Diabetes Police

Participants experienced tough love related to diabetes through policing behaviour by family, friends, and medical professionals. Participants frequently viewed parental figures as authoritative, policing forces in diabetes management who reacted with anger when blood sugars were out of range (P2, P5, P6). Parents were described as strict and lacking the tools to be emotionally supportive and available (P2, P5). Other forms of diabetes policing included “helicopter friendshipping” and the pathologizing of medical non-compliance by healthcare providers.

P5 referred to her mother as “the diabetes police,” and P6 reported being chaperoned by her mother at the doctor’s office, which frightened her out of asking about alcohol and diabetes. Her mother’s presence and related family strictness making such a question impossible to ask. As a result, P6 was not given space to ask for information that could have spared her distress. Like P5, P6 reported that her mother’s policing created an enduring lack of trust, which required her to expend emotional labour when navigating her mother’s interrogative questions about diabetes management. P6 said to me, “I love my mom, but I just lied to her. Then, she gets mad that I lied to her. I hate it when she asks me what my blood sugar is.” Here, it was evident that even present-day questions from P6’s mother about her diabetes carried the weight of past trauma.

Other forms of policing included “helicopter friendshipping,” pathologization of medical non-compliance, and feeling judged by family, friends, and medical professionals.

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P3 reported cutting ties with a friend who behaved in an overbearing manner and policed P3's diet. According to P3, her friend engaged in "helicopter friendship" to coerce P3 into better glycemic control. P3 felt as though she had to justify her choices to create a boundary with someone who assumed authority over her and her illness.

P1, P2, P5, and P6 recalled negative experiences in pediatric diabetes care, highlighting fear mongering, manipulation, and guilt tactics employed by their care teams to motivate better glycemic control. P1 recounted that the doctor would ask her parents why they weren't "controlling" her. This put strain on P1's support systems, namely, her family, who felt pressured to appease the physician. P1 indicated that all tactics failed because she was not yet prepared to invest the amount of emotional energy required to attain the strict glycemic control demanded by her doctor. She said: "I see the amount of work that I [now] put into it...I never could have done that when I was younger." This statement suggests that the effort required for ideal glycemic management is not realistic for all people at all times, and that pathologizing medical non-compliance is ineffective in addressing the problem.

P6 noted that "there was a habit of really making kids feel bad if their A_{1c}s weren't good." She expressed constantly feeling shamed. Resultantly, participants engaged in obfuscation and manipulation to avoid negative consequences. P1, P2, and P6 described lying, faking numbers, and doing whatever they could to avoid any kind of "scolding" or "trouble" from healthcare professionals. P1 noted that she was more concerned with getting into trouble than she was with her health. Medical professionals responsible for the patient's care were understood as adversaries whose scrutiny was to be evaded at any cost. Thus, participants expended emotional labour managing authority figures' negative feelings and reactions through avoidance tactics. As P1 emphasized, not managing diabetes was as much effort as managing it. P5 only recently began to view her endocrinologist as an ally rather

than an antagonist and continues to expend emotional labour grappling with the belief that her doctor secretly thinks she can do better.

P3 also expressed experiencing policing, judgment, and interrogative approaches from her adult family physician when her blood sugars were high. She indicated that healthcare providers acted as though the patient's knowledge of the consequences of high blood sugar would radically shift the patient's behaviour, which informed an interrogative and judgmental tone when the patient's behaviour did not shift. Participants emphasized the importance of not feeling like they must hide, justify, or excuse why their HbA_{1c} might be higher some months. As P1 noted:

I think that's been the driving force that has allowed me to feel safe [and allowed me to explore] new things, trying new technologies, and figuring out what works for me, and that's subsequently enabled me to have the best control I've ever had.

Overall, participants emphasized that policing behaviour was detrimental to their wellbeing, and that a collaborative rather than interrogative approach was key in fostering a positive relationship with healthcare providers, family members, and friends. Furthermore, policing behaviour eroded trust and may have led to the patient avoiding care or internalizing negative beliefs about themselves.

B. Managing the Police

Participants indicated that the policing and intrusive behaviour they experienced from family, friends, and medical professionals made them feel responsible for managing others' emotions, diffusing conflict, establishing firm boundaries, and over-empathizing with those who policed them. P5 speculated that her parents did not have a healthy or productive way of expressing how burdened they were from their child's illness. In recapitulating her friend's thought process, P3 said, "Diabetes caused it because you don't take care of yourself. You're going to die because you don't take care of yourself." This appeared to be a fear-based

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response, as P3's friend was signalling that she was afraid of the negative consequences of P3's behaviour. However, she communicated this by externalizing her fear onto the source of her anxiety (P3) and lashing out at P3. The primary motivation, then, was to modify P3's behaviour to allay the friend's fear of poor outcomes. This approach taken by P3's friend foisted responsibility for her anxiety onto P3, which resulted in a demand for P3's emotional labour. P3 further explained that her friends had at times become upset with her during hypoglycemic episodes, mistaking her behaviour as reflective of her feelings about them. Her friends' assumptions put P3 in a position where she expended emotional labour to soothe their insecurities and repair conflicts, making her responsible for managing the emotional states of the people policing her.

P2 indicated that she diffused conflict and coped with troubled familial dynamics by over-empathizing with her parents: "I'm being yelled at because mom is tired [or] had a really bad day. As long as I could identify why [my parents] were doing something that was unfair to me, I could be okay with [it]." This impulse to over-empathize in response to anger and policing likely contributed to feelings of excessive responsibility for herself and her mother. Over-empathizing was a coping strategy and a quintessential example of emotional labour. As suggested by Kelly et al. (2019), when marginalized people perform for the comfort of a hegemonic group, they are often required to empathize with that group. As seen with P2, empathizing with the people whose comfort she was attempting to maintain informed how she performed externally and how she rationalized and managed her own feelings. By over-empathizing with her mother's anger and distress, P2 internalized the belief that she was contributing to her mother's distress. This, in turn, resulted in P2's feelings of excessive responsibility for herself, and subsequently, guilt, shame, and alienation.

P5 articulated the continued importance of establishing firm boundaries with her family in response to their policing. She strongly believed that her family was not equipped

to emotionally support her, which led to their policing behaviour: “They will always feel like my diabetes police, so I just had to straight up be like, ‘Don’t talk about it with me because I’m not having it.’” This quote suggests that it becomes the chronically ill child’s task to set boundaries that will protect the child’s mental health and the parents’ mental health. It is also a way of diffusing conflicts before they can happen.

Furthermore, P6’s reported impulse to lie in response to policing behaviour could be understood as a tactic to circumvent performing emotional labour for her mother. If she answered her mother’s questions honestly, further interrogation and pressure on P6 to soothe her mother’s anxieties occurred—another form of emotional labour. As noted by Kelly et al. (2019), emotional labour is over-expended by marginalized groups to preserve the comfort of others, particularly those in a hegemonic position. Because a parental figure holds much of the authority and power in a child’s life, and this dynamic may persist even into the child’s legal adulthood, it becomes the child’s responsibility to manage the feelings of the parent (e.g., P2 and P5).

Theme 2: The Need for Mental Calculus

The term “mental calculus” was co-created between the participants and was discussed with six of the nine participants (P1, P2, P4, P6, P7, and P9) and was used to describe a decision matrix that they felt they must engage in when interacting with others. This decision matrix was primarily associated with casual acquaintances and coworkers who were not well-informed about diabetes and strangers who were not well-informed about diabetes. “Mental calculus” was described in three primary settings: when the participant with diabetes felt pressure to educate or empathize with an uninformed acquaintance, coworker, or stranger (all here considered laypeople in that they typically lack knowledge about diabetes), and when the participant felt pressure to disclose to laypeople that they had diabetes to laypeople.

A. Educating and Empathizing With Laypeople

Six of the nine participants (P1, P2, P4, P6, P7, and P9) identified performing “mental calculus” when engaging with laypeople who may be un/misinformed about diabetes, particularly when comments by laypeople warranted corrections, education, or an expression of empathy. Laypeople refer to coworkers, acquaintances, and strangers and excludes close relationships such as family, close friends, and romantic partners, who will usually have at least some working knowledge of diabetes.

When strangers asked P1 about her medical devices in public, she asked herself, “Should I educate this person, or should I enjoy my Sunday?” Here, it became clear that P1 associated educating laypeople with potentially negative emotional experiences. She described feeling forced to choose between an unpleasant obligation to educate and continued enjoyment of her day.

P2 also reported performing “mental calculus” to assess the purpose and potential outcome of conversations intended to correct those misconceptions or stereotypes. She found herself asking whether her intervention would change anything and checking her emotional capacity for engagement. This ongoing “checking-in” with oneself while simultaneously evaluating the temperament of laypeople and their receptivity to being corrected represented a massive expenditure of emotional labour. She articulated that this mental calculus was a source of emotional labour because she was constantly adjusting her behaviour not only to protect herself but to protect others; she expressed not wanting to embarrass other people and thus expended emotional labour to protect their feelings.

Participants also protected strangers from exposure to diabetes management that occurred in public. P6 said it was “exhausting to try to change things you need to do just to keep yourself alive. Because you’re worried about how people around you are going to respond, and that really sucks because you’re policing yourself.”

P4 and P7 also expressed frustration with having to educate others. P4 indicated that she did not always have the energy to do so, and said, “I don’t feel that I should be the one that has to take on the emotional burden of being the fact police and dealing with being on an educational crusade.” P7 reported expending emotional labour on making judgment calls about how much she wished to invest in teaching a layperson, and she based this judgment on how receptive she thought they would be or if she would end up in an unwanted interaction. P7 described this mental calculus as a substantive process that occurred internally without the other person’s knowledge whereby, she considered the appropriate level of disclosure, the potential reaction, and whether the outcome was worth the labour. P7 expended emotional labour on applying an individualized approach to decision-making; thus, each individual she encountered warranted potentially different treatment. This also illustrated the energy-consuming decision matrix.

B. Making Diabetes Legible and Proving Trauma

Three participants expressed struggling to make diabetes legible when others presented reductive or unnuanced perspectives. Here, I use “legibility” to refer to how participants work to make a complex condition understandable to people who do not have to engage with that condition. Participants emphasized the complexity of diabetes and what they perceived as others’ unwillingness to engage with this complexity. Furthermore, participants expressed feeling pressured to prove that they had suffered trauma from living with diabetes. These demands, coupled with the impulse to oversimplify diabetes, contributed to participants’ feelings of alienation and their over-expenditure of emotional labour.

P3 told me that her friends were not well-informed about diabetes and had superficial working knowledge of the illness. She expressed no major difference between her friends’ depth of understanding and strangers’ depth of understanding. This lack of distinction between friends’ and strangers’ knowledge may imply some degree of alienation from peer

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groups. In P3's view, people did not grasp the intricacies of diabetes due to the complexity of management and the sheer volume of information required for understanding. However, P3 expressed being generally unwilling to do extensive labour to make diabetes legible to others.

To receive understanding from others who hold a reductive view of diabetes, P5 and P6 reported feeling as though they had to prove that their illness created personal suffering. P6 expressed that misinformation and well-meaning questions alike made her feel as though she had to "prove" her trauma to have her struggles around diabetes rendered valid. P6 recalled a peer who said to her, "You can't have problems; you're blonde and pretty," and reported that this comment spurred resentment in P6 and the sense of having to "prove [her] trauma" to others. P5 also expressed that she struggled against the impulse to prove that she was suffering so that her diabetes could be understood and taken seriously. P5 described doing excess work to explain diabetes to people— akin to emotional labour. P5 said that she overexplained diabetes to others to help them understand her situation and to prove that diabetes created hardship for her, but she would grow frustrated when they did not demonstrate understanding. To combat this impulse, she invested her emotional labour in managing her expectations of others. P5 articulated that she had to teach herself to set boundaries with herself and decide how much she was going to invest in eliciting compassion from others.

P6 also reported that explaining diabetes to people and managing their expectation that information ought to be easily digestible constituted emotional labour. She said it was "really frustrating...to communicate [diabetes] in a way...they'll understand." She emphasized multiple times in the interview that the task of making diabetes and her suffering from diabetes legible to other people was her greatest source of emotional labour. To accomplish this, she felt she had to be willing to disclose her traumatic experiences to justify her struggle using categories that were legible to those who did not have to engage with

diabetes. It is important to note that P6 used diabetes and trauma interchangeably throughout this conversation. I pointed this out to her and asked if she considered diabetes a kind of trauma, to which she responded, “Yes.”

C. Disclosure

Speaking with laypeople when disclosure became a possible outcome also involved a “decision matrix” for participants and required emotional labour for four participants (P1, P3, P4, and P7), who continuously found themselves in a position where they overexerted emotional labour to maintain the comfort of a hegemonic group.

For P1, “mental calculus” came primarily in the form of what she termed “forced disclosure.” Despite efforts to hide devices, the functions of her medical equipment, such as beeping and other alerts, prompted innocent questions that forced disclosure. Subsequently, P1 engaged in mental calculus to decide how much to disclose.

P3 told me that on dating apps she often provided “bare bones” answers to people who asked questions about her diabetes, responding with “I have to take insulin when I eat.” She related that it took effort to fully explain diabetes, and that she did not want to disclose details about her diabetes complications. This approach, while protecting P3’s time investment, nonetheless created an additional layer of labour because she had to determine level of disclosure.

P4 described in detail her decision to disclose her diabetes to a university peer when they made an insensitive comment about diabetes: “Either I say nothing and then she finds out later [that I have diabetes] and feels bad, or I tell her now and hopefully she learns.” Here, P4 was forced by her peer’s insensitive comments to weigh which scenario would cause her peer the least discomfort, prioritizing her peer’s feelings over her own. The peer unknowingly created a demand for emotional labour from P4, who understood that she could not indefinitely hide that she has diabetes.

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P7 provided a fascinating anecdote on how the COVID-19 pandemic impacted her professional life and intensified the need for mental calculus via disclosure. In 2020, she and fellow employees were asked to share their health concerns, and P7 struggled deciding if she wanted to disclose that she had diabetes and how the illness impacted her health concerns regarding COVID-19. She reported feeling afraid that she would be thought of differently if she disclosed her diabetes and that voicing her concerns would create the impression that she could not perform her job. She reported being concerned that the president would assume she wanted accommodations and that she “didn’t want him to judge me on these misconceptions.” This demonstrated an implicit view of accommodations as something undesirable that sick people requested. Thus, P7 felt she had to prove that she could function without accommodations because this would demonstrate her value to the company.

Theme 3: Managing Misconceptions From Laypeople

All nine participants reported that managing misconceptions from laypeople required emotional labour. In many instances, the misconceptions themselves proved to be hurtful or offensive, and the participants’ emotional labour seemed primarily invested in managing their own feelings around these misconceptions and navigating how to respond to them. Misconceptions included hurtful and offensive comments, misinformation, reductive understandings of diabetes that elicited pressure to prove one’s trauma and make diabetes legible, the conflation of T1 and type 2 diabetes, and reactions (both experienced and potential) to visible medical devices. It is important to note that there is a substantial degree of overlap between these sub-themes. For example, hurtful and offensive comments are often rooted in misinformation, as the conflation of T1 and type 2 diabetes constitutes misinformation.

A. Hurtful and Offensive Comments

Three participants emphasized the role of inappropriate, hurtful, or offensive comments, jokes, and scrutiny for personal choices. Such comments created an incongruence between participants' self-concept and how they were perceived by others. As a result, participants expended emotional labour to manage their personal reactions and responses to hurtful and offensive comments.

Participants described dehumanizing comments, such as comparisons to robots and, in the case of one participant, being asked if she needed to "plug herself in at night." Offensive comments occurred so frequently that participants expected others to be ill-informed and calculated their responses accordingly. P7 provided an anecdote about someone surmising from her insulin pump tubing that she had T1 diabetes and commenting, "Oh, so you'll never be able to have children." Such insensitive and untrue comments created an incongruence between how P7 saw herself and how other people may have viewed her. Comments overstating or joking about limb amputation and diabetes (P7, P4, P1) revealed a reductive and stereotyped understanding of diabetes that was likewise incongruent with participants' self-concepts. Because of this incongruence, participants expended emotional labour to manage their reactions to misconceptions and calculate how to respond without being condescending or moralizing.

P7 had also received scrutiny for her dietary choices, which were primarily to better manage her glucose. For example, lower carbohydrate meals throughout the day allowed her better glycemic control with less physical and mental labour. However, laypeople who witnessed her eating patterns sometimes asked implicitly derisive questions or made comments that she was "eating keto," which she felt ascribed an association with vanity and a value judgment to low carbohydrate diets. However, P7 reported not having the energy to explain her dietary choices to people and felt that she should not have to. These examples

demonstrated that P7 received scrutiny about her dietary choices as though she were able-bodied, even when people knew she has diabetes. P7 had to then expend emotional labour to manage her feelings around being wrongly perceived as someone who was dieting for vanity. Furthermore, she felt she had to respond to individuals who made these comments in a way that preserved their comfort, which was yet another demand for emotional labour. P7 reported resenting external scrutiny that accompanied the already exhausting task of diabetes management. Her response to offensive comments was to “shut down,” which constituted another form of emotional labour, as it was her strategy to keep her emotional equilibrium. Rather than externalizing her frustrations, she internalized and suppressed them while re-evaluating her expectations of laypeople.

B. Misinformation

Seven participants (P2, P3, P4, P5, P7, P8, and P9) expressed that encountering misinformation was a common occurrence that demanded their emotional labour. These included incorrect beliefs about diet, complications, and health outcomes. When encountering misinformation, participants differed in their responses, though most used “mental calculus” to decide whether to and/or how to respond.

P4 recounted that many of her university health science textbooks presented reductive perspectives on diabetes, which exacerbated existing stereotypes held by her classmates, who were healthcare professionals in training. Participants reported trying to keep her diabetes invisible because she did not want people giving her well-intentioned misinformation (P4, P7). P7 expressed avoiding diabetes as a topic of conversation because she did not want to listen to misinformation about her condition or unhelpful opinions. Furthermore, she considered the cost of correcting misinformation and the negative reaction this may elicit in the other party, all constituting emotional labour.

Participants expressed expending emotional labour managing misinformation about diet and diabetes, specifically, the culturally ingrained belief that people with diabetes cannot eat sugar or carbohydrates (P2, P3, P8, P9). P2 recalled correcting stereotypes when parents and peers would attempt to restrict her diet. P3 reported being interrogated by friends about her choice to eat carbohydrates, and P9 reported feeling as though people might judge her for eating sweets. Managing the negative emotions that arose from these encounters required emotional labour. Furthermore, while P9 reported no longer having the emotional bandwidth to extensively explain diabetes, P3 explained that these gaps in knowledge, and others' refusal to accept their lack of knowledge, had led to interpersonal conflict.

P8 also reported being asked multiple times if she has diabetes because she ate too much sugar as a child—a common misconception that perpetuates the idea that diabetes is a lifestyle illness that results from poor choices. P8 self-identified as fat and expressed concern that her weight reinforced the idea that people with diabetes are fat. The intersection of T1 diabetes and fatness created unique challenges for P8. Comments such as, “I’m going to go to this dessert place, and it’ll give me diabetes,” would be frustrating to many people with T1 diabetes, irrespective of their weight, but for P8, it created extra emotional labour as the comments were offensive on two fronts, which compounded stigma and alienation.

C. Conflation of T1 and Type 2 Diabetes

A lack of familiarity with T1 diabetes and broadly disseminated stereotypes about type 2 diabetes in cultural imaginary have led to the common conflation of these two illnesses and is a source of social stigma for people with T1 diabetes (Jeong et al., 2018). Four of the participants (P4, P7, P8, P9) identified this conflation, a type of misinformation requiring expenditure of emotional labour.

Participants expressed frustration with this conflation and reported witnessing misconceptions and a widespread lack of knowledge about juvenile/T1 diabetes and

described the emotional labour to navigate their reactions to being mistaken for having type 2 diabetes (P7, P8, P9). Even some medical texts at the university level do not distinguish between the two types (P4). Because there are so many negative connotations ascribed to type 2 diabetes, such as the costs of healthcare and the alleged burden to the healthcare system, laypeople tended to view type 2 diabetes as a “lifestyle” illness and a burden to society. Thus, people with type 2 diabetes are thought to be ill because of their poor choices, and society pays the cost. P7 received comments such as, “But you’re so thin,” in response to her disclosing that she has diabetes. Laypeople often expressed confusion that P7 did not fit negative stereotypes of diabetes, which demonstrated how people with type 2 diabetes are often blamed for their diagnosis. P7 disliked such comments because they demonstrated an implicit value judgment against people with diabetes. As a result, she expended emotional labour to manage what felt like attacks on her self-concept.

D. Visibility of Medical Devices

Four participants (P1, P2, P5, and P9) expressed past and/or present discomfort with the visibility of their medical devices. This discomfort was largely informed by negative experiences, such as people asking inappropriate questions or making incorrect assumptions about the purpose of the devices. Furthermore, these past experiences informed concerns about future interactions, motivating participants to keep their medical devices as invisible as possible.

P1 reported doing everything in her power to hide her devices to avoid questions from strangers. P2 reported hiding her medical devices when she was child due to internalized shame about having diabetes. She expressed having intense childhood anxiety around being visibly diabetic: “I put myself through so much physical discomfort because I didn’t want people to see it, because if they saw it, they were going to stereotype me.”

P5 described feeling shame because of her visible diabetes devices. She recounted an incident when two other women loudly asked one another, “What do you think is wrong with her? She must be super sick. That [the device] isn’t normal.” P5 decided to approach them and explain what the device was for and highlighted this as a pivotal moment in helping her be more open about her illness. She told me that she is now less fearful of judgment and understands that how other people speak and think about her diabetes reflects more on them than on her.

P9 reported feeling uneasy in public spaces such as restaurants after her diagnosis and said she did not want people to see her using her medical devices in case they had a needle phobia. Thus, P9 made every effort to ensure that her diabetes was as invisible as possible. P9’s impulse to privilege the comfort of a stranger who may or may not have a phobia of needles is consistent with Kelly et al. (2019)’s findings that marginalized individuals expend emotional labour to maintain the comfort of others, particularly those who belong to a hegemonic group. In public spaces, laypeople constituted the hegemonic group because most do not have T1 diabetes.

E. Ableism

Participants reported experiencing ableism both in healthcare settings and interpersonally, such as provider discomfort with concurrent youth and sickness and the foreclosure of social possibilities (P2, P3, P4). P3 expressed a strong dislike for responses in healthcare settings such as, “Oh, but you’re so young,” when she disclosed that she has diabetes. As she said to me, “Yeah, young people get sick.” Healthcare providers’ uninterrogated expectations that young people ought to be healthy became a source of stress and emotional labour for P3, who was caught between her negative emotional reaction and the opportunity to correct misinformation about T1 diabetes. She told me that nurses have said to her, “you shouldn’t be this sick,” and explained that such disbelief at her lived reality

was an unnecessary reminder of her difficult circumstances. These comments from healthcare providers, which framed P3's life as a tragedy, revealed ableist assumptions about what constitutes a life of thriving. P3 expended emotional labour to process these comments and what they implied for her mortality and quality of life.

Participants indicated that ableism also impacted interpersonal dynamics, including the loss of romantic relationships because of their partners' unwillingness to engage with their diabetes (P2, P3, P4). Participants invested considerable emotional labour in accommodating ableist perspectives to protect their emotional and mental well-being while dating or seeking potential romantic partners. P2 and P3 described having romantic partners who simply did not wish to engage with the illness or did not wish to be with a chronically ill person and left the relationship as a result. These relationships not only created and compounded diabetes-related trauma for P2 and P3 but produced an increased demand for processing and managing their emotional responses.

Due to her experiences, P3 described feeling that she had to disclose her diabetes to filter potential partners who may hold ableist views or may be unwilling to adequately invest in a relationship with a chronically ill person. P3 showed an unwillingness to navigate ableism at all; she did not seem to care to be understood by people who may reduce her to her illness. However, her disclosure invited questions, which became an additional demand for P3's emotional labour with individuals she had never met. P3's approach, while protecting her from rejection due to her diabetes, nonetheless created additional labour by virtue of her having to determine level of disclosure.

P4, in contrast, tried to avoid disclosing her diabetes. In discussing her dating life, P4 said, "Even if I didn't have any internalized ableism, people do have that." P4 repeated several times that she did not want to be seen as synonymous with her illness. She was aware that others may see the illness as something undesirable, or as something that detracted from

her appeal as a person. Thus, she wanted the diabetes to be understood as incidental and separate from her other qualities.

Theme 4: Systemic Barriers

Eight of nine participants (all but P1) expressed that people with tT1 diabetes have added stress with added layers of bureaucracy to navigate to access care. Frequently, they had to demonstrate compliance and prove that they were “valuable” enough to be entitled to financial aid and access to life-saving medical devices. Furthermore, rigid notions of compliance presented barriers for access to medical procedures. Poor social and institutional understandings of T1 diabetes also resulted in inadequate models of disability and risk assessment, which further impacted participants emotionally and psychologically. Navigating systemic barriers included working within these limitations—specifically inadequate theoretical frameworks—was identified as a source of emotional labour for participants. Finally, medical assumptions by healthcare providers led to inappropriate care.

A. Access to Medical Devices

Three participants (P3, P5, and P9) identified institutional and bureaucratic requirements such as age limitations, proving compliance, and “jumping through hoops” to access medical devices on their own timeline as a source of emotional labour. They noted that these barriers created additional stressors for their diabetes management.

P5 described institutional pressure to acquire a pump before she was eighteen because in her province, only those who began using an insulin pump prior to their eighteenth birthday would continue to receive funding into their adult years (Government of Quebec). As a teenager, she was resistant to the pump for aesthetic reasons but felt wrangled into acquiring one before she was emotionally ready. She identified contending with this pressure as a source of emotional labour for her teenaged self and expressed that it was an undue burden that compounded already existing diabetes-related stressors.

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In reference to government funding programs for diabetes patients who demonstrated compliance, P3 said of herself, “I’ve never been able to prove I’m a good enough diabetic to get [the pump].” Furthermore, P3’s description demonstrated that institutions and bureaucracies reinforce problematic categories like “good diabetic” and “bad diabetic” by imposing stringent requirements on people with diabetes to prove that they are managing their illness well enough to receive additional care.

P9 echoed these sentiments that people with diabetes must “jump through [arbitrary] hoops” to receive devices or treatment that would improve quality of life or glycemic management. She highlighted that bureaucracies demand proof that a treatment or device is truly necessary and “deserved” by the patient. However, as P9 pointed out, the devices that one must prove compliance to receive were usually the ones that enabled one to comply to medical regimes more easily. P9 reported that this catch22 constituted a huge source of emotional labour.

B. Access to Non-Diabetes Related Procedures and Common Privileges

Two participants discussed regulations aimed at people with diabetes that prevent them from accessing non-diabetes related medical procedures and common privileges such as elective surgeries and drivers’ licenses. Although these regulations are in place ostensibly to protect both the individual with diabetes and those around them, they negatively impacted participants by creating additional demands upon them. Navigating these demands was identified as a source of emotional labour.

In P2’s province, people with T1 diabetes must receive a medical evaluation to acquire a driver’s license. P2 recounted having a general practitioner who seemed unaware of the degree to which blood sugars fluctuated in people with T1 diabetes. The doctor, holding unrealistic expectations and the incorrect belief that people with T1 are not permitted to drive, refused to sign the necessary documents that would allow P2 to pursue acquiring her

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driver's license. The doctor eventually relented, but under the condition that P2 could demonstrate that she experienced no more than three high blood sugars a week. This is problematic, as "high blood sugar" constitutes a massive range; most elevated blood glucose (barring extremes and ketoacidosis) bears no short-term consequences or ill-effects for the patient. It is, in fact, hypoglycemia that poses a risk to safety while driving, as a severe hypoglycemic episode can lead to disorientation, confusion, and loss of consciousness. Being made to challenge a doctor's medical knowledge and understanding of provincial laws constituted emotional labour, as P2 had to evaluate the ideal method of communication that would maintain social propriety, protect the physician's ego, and elicit the desired results.

Furthermore, P9 was denied surgery for three years over what she described as an arbitrary requirement to have an HbA_{1c} below 7%. As a trans woman with T1 diabetes, P9 offered a highly valuable and unique perspective on the bureaucratic and institutional barriers that intensified emotional labour, as this intersection changed her interactions with the healthcare system. P9 began her medical transition two years after her T1 diabetes diagnosis, and when she decided to pursue gender affirming surgery, she was met with barriers that prevented her access to surgery and made it more stressful for her to manage her T1 diabetes. She described the process as "having to jump through a pile of hoops." For example, P9's HbA_{1c} was 7.2%, which her endocrinologist agreed was no riskier for surgery than a 6.9%, but P9 was denied surgery regardless.

It is worth noting the shortcomings of HbA_{1c} tests as an accurate measure of glycemic control over the long term. HbA_{1c} tests do not account for glycemic variability between hours, days, or even weeks (Saboo et al., 2021; Klein & Buse, 2020). Furthermore, "HbA_{1c} does not distinguish individuals with similar average glycemia but with pronounced differences in hypoglycemic events and/or hyperglycemic excursions" (Gabbay et al., 2020). This means that individuals who are "in range" 75% of the time with few

hypo/hyperglycemic episodes and those who are in range 50% of the time but experience a high frequency of hypo/hyperglycemic episodes can attain a similar HbA_{1c} result. Therefore, the well-established shortcomings of HbA_{1c}s as an absolute measure of glycemic control render it a poor assessment tool for risk of surgery complications when wielded rigidly, as it is possible for a person with an A_{1c} of 7.2% to have more stable and in-range day-to-day glycemic control than someone with an A_{1c} of 6.9%. The rigid requirement of an A_{1c} below 7%, then, created undue systemic barriers for P9 to access an important surgery. Despite her endocrinologist's advocacy, it nonetheless took three years for P9 to receive surgery.

C. Institutional Definitions of Disability

Three participants expressed that interacting with institutional definitions of disability and accommodations procedures was a source of emotional labour. Definitions of disability were identified as too rigid and lacking a sufficiently nuanced framework. Furthermore, the act of asserting one's right to accommodations in relation to these frameworks was identified as a source of emotional labour.

P6 and P8 both characterized institutional and bureaucratic definitions of disability as frustrating, reductive, and limiting. The Government of Canada requires people to engage in or manage their condition for a minimum of fourteen hours a week to qualify for certain disability benefits. Perhaps ironically, T1 diabetes is used as an example on the Canada Revenue Agency website, which states that "the time spent on activities directly related to determining the dosage and administering the medication **can** be counted in the 14 hours per week requirement" (Canada Revenue Agency). The subsequent examples from the CRA include: "checking blood glucose levels; preparing and administering insulin; calibrating necessary equipment; testing ketones; keeping a logbook of blood glucose levels" (Canada Revenue Agency). Both P6 and P8 noted that this framing does not make sense for people with diabetes, who P8 described as being "constantly on," and not merely when they are

performing the physical labour of diabetes management. Participants noted that measuring out the number of hours spent on the illness was an impossible task, as their entire lives revolved around management. Here, the CRA's examples rather glaringly omitted the inherent cognitive and emotional components of management. Thus, there is a great deal of invisible work and emotional labour that goes into managing diabetes that is unaccounted for in institutional definitions of disability.

P6 noted that institutionally, she qualifies for disability tax benefits but said she feels relatively able-bodied. The conditional aspects of disability for people with diabetes become a source of emotional labour in that being able-bodied is never a given. Rather, people with diabetes—especially those engaged in discourse on disability—must constantly evaluate their relative health and their ease of access to hegemonic spaces to define and redefine themselves. P6 noted that she does not feel entirely comfortable identifying as disabled and does not like the term “invisible disability” notions of “visible” and “invisible” disability reveal assumptions about how disabled people ought to present and perform. She also pointed out that, “I’m able-bodied, but if you have to have things attached to your body in order to stay alive, are you really able-bodied?”

Here, P6 identified grappling with a false binary: that of being able-bodied or disabled. She expressed that neither category fit her. Likewise, when P7 began her job, she was required to fill out forms that included questions about whether she has a disability. Regarding this, P7 said, “On the one hand, I want protection. I want all the rights that I can have. But at the same time, I don’t want to call attention to it.” She felt that the term “disabled” had a different connotation from chronic illness and reiterated some of P6’s sentiments: “I feel like I’m pretty able-bodied 90% of the time.” Here, P7 referred to what I call conditional able-bodiedness. That is, if certain conditions are met—if one wears an insulin pump and has access to a glucose metre or continuous glucose monitor (CGM)—then

one can generally function as though able-bodied. Nonetheless, P7 emphasized repeatedly that she did not want to be different.

The conditions of one's employment were also identified as a privilege or a barrier to accessing the right care. P8 noted that asking for time off required a emotional labour, especially for those who wanted to appear healthy and "low maintenance" in the workplace. P8 noted that "you need to give yourself permission" to ask for accommodations. This echoed P7's relationship to her workplace and her fear of being seen as someone who needs accommodations. Taken together, these examples highlighted an important intersection between institutional barriers, broader misconceptions about diabetes (and disability at large), and the need for people with diabetes to perform "mental calculus" to navigate these social and institutional spaces.

D. Medical Assumptions

Participants noted that medical assumptions rooted in inadequate knowledge about T1 diabetes created systemic barriers to proper care, which compounded their expenditure of emotional labour. Such incidents included assuming causal relationships between diabetes and an acute illness, misdiagnosis, alarmist thinking, and a poor grasp on the interaction between comorbid conditions (P2, P4, P6).

While combating an ear infection, P4 dealt with a general practitioner who advised taking an ambulance to the hospital for her high blood sugar, which is common with infection. She reported being made to sign a waiver acknowledging her risk of death for not following the doctor's advice to go to the hospital. This incident demonstrated that some non-specialists are disconnected from the lived experience of people with diabetes, which in turn informs inappropriate medical opinions or advice. P2 likewise recounted an experience with a general practitioner whose knowledge of T1 diabetes was so poor that they had P2 tested for HIV when she was experiencing chronic yeast infections from elevated blood glucose. The

doctor's assumptions not only prevented P2 from receiving the proper care, but she expended emotional labour navigating her physician's judgments and managing her own responses. In both instances, acute health concerns were blown out of proportion because of the presence of diabetes. Furthermore, healthcare providers' assumptions about health more broadly can prolong diagnosis and have detrimental physical, mental, and emotional effects on patients. P4 expressed feeling failed by the healthcare system over the course of her excessively lengthy diagnosis, which took approximately four months and was exacerbated by her physicians' unwillingness to consider T1 diabetes as a possibility for an adult patient. P4 suspected that she had developed diabetes, however, her doctor believed she was "too old" for T1 and "too healthy" for type 2, despite an elevated HbA_{1c} of 6.3%. Yet up to half of new T1 diagnoses occur in adults (Leslie et al., 2021), and in many instances, adult-onset T1 diabetes presents with "a more gradual onset of hyperglycemia, often leading to misclassification and inappropriate care" (Leslie et al., 2021, p. 2449), which was consistent with P4's experience of gradual weight loss and worsening HbA_{1c}s. Many adults with T1 diabetes initially do not need insulin therapy and experience. Alarming, misdiagnosis occurs in approximately 40% of adults with T1 diabetes, and the risk of error increases with age (Leslie et al., 2021, p. 2449). Furthermore, the long-established but problematic association between low body mass index and good metabolic health has contributed to a medical culture in which illnesses that are reductively understood as lifestyle-related are overlooked for patients who are thin and therefore assumed to be healthy. In P4's situation, the misdiagnosis was not merely physically detrimental but whittled away her ability to cope with the illness. P4 was misdiagnosed with type 2 diabetes and PCOS twice before she received the correct diagnosis of T1 diabetes, which could have come months sooner had her doctors not been so resistant to requisitioning a simple blood test to check for T1 diabetes markers.

P6 emphasized that comorbidities created additional emotional labour for her because of the layers and intersections that needed to be explained to medical professionals to prevent poor medical decisions. For example, when P6 struggled with an eating disorder, she experienced pressure from an eating disorder pediatrician to switch from daily insulin injections to an insulin pump. However, P6 deduced that this was unsound and ill-informed medical advice based on reductive assumptions about the benefits of an insulin pump. A systemic review by Priesterroth et al. (2021) concluded that there is almost no scholarly literature exploring the impact of insulin pumps on “diabulimia,” and that most evidence is observational and heterogeneous (p. 10-11). However, the review noted that continuous subcutaneous insulin infusion (i.e., insulin pumps) were discontinued more frequently in people with eating disorders. Furthermore, a 2017 report published by the advocacy group, Diabetics with Eating Disorders (DWED), indicated that insulin pumps triggered body image issues and served as a constant reminder of the illness, thereby exacerbating the link between diabetes and disordered eating behaviour (Kearns & Allan, 2017). Insulin pump education also results in an increased focus on factors that inform the psychology of disordered eating and body dysmorphia. For example, the report compiled by DWED noted that, “The necessity of techniques such as carb counting may lead to or add to obsessional thoughts.” (Kearns & Allan, 2017).

Theme 5: Intrapersonal Relationship to Diabetes

All nine participants indicated that diabetes informed their relationship to themselves. I have chosen to refer to this more broadly as the intrapersonal relationship to diabetes, which encompassed the inner life of the participants as it pertained to their diabetes. This included facets such as how a person with diabetes relates to their illness, the kind of relationship they build with diabetes (and how that relationship changes), how their experience with diabetes

may inform their identity, and what core beliefs the person may internalize about themselves as a result of diabetes management.

A. Unpredictability of Diabetes

Four participants (P2, P5, P8 P9) highlighted the unpredictability of diabetes as a source of stress that warranted emotional labour to manage, specifically, the innumerable variables they needed to account for and their inherent distrust in their own body's functionality. Participants described experiencing anxiety as a natural consequence of living with diabetes due to the plethora of unpredictable factors. Mundane activities such as going for a walk or going to bed are wrought with uncertainty, which created distrust in one's body because of the amount of effort required to make it function (P5, P2, P8). P5 explained, "I don't have trust in my body to be able to do basic human things." While able-bodied individuals do not think about their body's functionality (a largely passive process), a person with diabetes needs to prepare for a worst-case scenario whenever they choose to engage in an activity, whether it be taking a walk or merely going to sleep (P5, P8). For participants, diabetes was not only a great deal of physical and mental labour (e.g., preparing for a worst-case scenario) but it was took emotional labour to process and cope with the anxiety and distress that arose from this physical and mental labour.

P9 also characterized the constant presence of diabetes as similar to having a child and expressed frustration with the "roller coaster" of having high blood sugars (i.e., a child) that would not drop (i.e., cooperate) despite aggressive corrections, followed by sudden "crashes" into hypoglycemia. When I asked her to describe diabetes in three words, she said immediately, "Well, f*ck me," then went on, "It's stupid and sh*tty, but it's not going away." She expressed feeling as though there was little rhyme or reason to glycemic management, and that she was always reacting to circumstances and hoping for the best. However, because there were too many variables, it always felt like a guessing game for P9.

B. Mental Health, Burnout, and Emotional Exhaustion

Four participants (P1, P5, P6, P7) expressed experiencing burnout or emotional exhaustion pertaining to diabetes. This exhaustion was partly the result of expending too much emotional labour; however, exhaustion itself created a demand for its further expenditure. Participants described contending with anxiety, depression, and disengagement related to diabetes, which was both a function of exhaustion and contributed to it. Emotional labour was thus expended both to cope with these mental health complications and to process the exhaustion they created.

P5, who was diagnosed at age two, has predominantly negative memories of living with diabetes as a child and described battling depression, anxiety, and eating disorders in her teen years. Only in her twenties did she feel emotionally ready to unpack her childhood trauma around diabetes, and she described continuing to struggle finding time and energy to productively manage her negative emotions around the illness. She described becoming angry with people suggesting she “chill out” or talk about her distress. She said to me: “I don’t have time to chill...I don’t have time to talk about this. If I want to talk about it, I’m not taking care of myself. I’m just tired. I’m tired of it. Nothing is ever easy.”

P5 positioned speaking about her negative emotions as being oppositional to self-care. She drew a contrast between physically taking care of her diabetes and talking about how diabetes makes her feel. P5 expressed that if she “stops to talk about it,” she won’t be able to maintain her emotional equilibrium, which could derail her glycemic management. These comments were made in tandem with an emphasis on being tired and suggest that the fragility of this equilibrium is in part a function of being emotionally exhausted. She confessed to feeling scared that if she began talking about her feelings, she would return to “the dark place” from her teenage years when she was overwhelmed with negative emotions (which

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informed self-destructive behaviour) and had no toolkit to process or navigate those behaviours and emotions. Regarding this fear, she said to me:

Everything about diabetes [is] unforgiving. It's there 24/7, it doesn't care if you need to get a good night's sleep; it doesn't care if you're going on a first date; it doesn't care if you're running a marathon; it just doesn't care. So, I think it's kind of affected my mentality and how I deal with it. Even if I'm emotionally drained, and I feel like I don't have the energy to change my pump site or change my CGM site, it's kind of like, you don't have that luxury. You have to keep on going, otherwise, you're tip toeing the line of going back to who you were before.

P5 expressed that therapy (though she did not disclose when she began therapy or whether it was ongoing) had helped her tremendously with her diabetes-related struggles but warned that it too was a form of emotional labour, expressing that she was in therapy because others in her life were not. P5 felt that she had to expend emotional labour where those in her life were unable or unwilling to, and this further compounded her emotional exhaustion.

Participants reported experiencing periods of burnout and depressive episodes that hindered their ability to manage their blood glucose (P6, P7). This resulted in infrequent blood glucose level checks and apathy towards glycemic management, despite acute awareness of the consequences. P6 noted that so much of her emotional labour was invested in processing and navigating her burnout and depression, so diabetes became less of a priority. P6 described the task of keep herself alive via glycemic management as a losing battle. P7 described her teen years as filled with "poor choices" and noted that she did not want to be think about or be burdened with glycemic management during her adolescence. However, she expressed gratitude that she survived that period of her life. She expressed that presently, even the act of taking out a test strip for her glucose meter was exhausting. Furthermore, she described compensating for years of poor glycemic management with tight

glycemic control out of fear that she damaged her body. P7 also drew a stark contrast between the broad acceptance of diabetes technology as a mechanism to improve control and the emotional impact of the technology on the person using it. She noted that high/low blood glucose alerts on her CGM are disruptive to her sleep and created a constant awareness of her illness. As a result, the alerts incited anxiety, which then demanded emotional labour for management. Thus, even when P7 is investing her emotional and mental resources in managing her blood glucose well, she experiences a constant drain. P1 was also emphatic about this point in her interview and said that managing diabetes well was as exhausting as managing anxiety and fear during periods of poor management. While discussing burnout, P1 provided a poignant and telling statement:

I think the emotional labour feels [like] more than it ever [did], with educating others, interacting with my partner [and] various different people, **and also within myself** [emphasis added]. I feel the emotional weight and the emotional labour of having type one diabetes now more than ever, even though things are better now than they've ever been.

P1's statement suggested that diabetes distress increased the more engaged a person was with their illness, and that this might be associated with the amount of emotional labour they felt compelled to invest.

C. Physical Impacts

Seven participants (P1, P2, P3, P6, P7 P9, and P8) noted that the unpleasant physical impacts of diabetes affect behaviour and emotional well-being. Furthermore, participants identified managing this relationship between physical and emotional wellbeing as a source of emotional labour. Participants expressed frustration with fluctuating blood glucose (P1, P2, P7, and P9). P1 and P2 identified erratic blood glucose as their “worst diabetes days” and felt they had to expend emotional labour to manage the negative emotions that arose as a

result. For P3, her worst diabetes days, “means some sort of pain...for example, my neuropathy will be acting up and I can’t walk.” Furthermore, for P3, P7, and P9, losing sleep from erratic blood sugars contributed to diabetes-related frustration. P7 reported that fluctuating blood sugars overnight are a source of major frustration; her sleep is interrupted, and the physical toll of high blood sugars, such as tiredness and dehydration, compounded this frustration. Moreover, due to a lack of comprehensive diabetes education in the adult healthcare system, P3 experienced more physical complications, which meant that she invested more emotional labour managing negative emotions that arose from living with physical complications. Her worst days with diabetes were physically taxing, impacted her autonomy, and contributed to feelings of depression, frustration, and lack of motivation.

P9 and P6 touched on how negative physical experiences, such as hypoglycemia, informed fear and anxiety about future events. P9 described hypoglycemia as such: “You feel like you’re dying. Your body is literally like, ‘Sh*t, guys, everything is going down. The ship is sinking. This is it; we’re done.’” The physiological response to hypoglycemia is so uncomfortable that it fuels fears and anxieties around experiencing it and being unable to correct it. P6 experienced a traumatic, near-death diagnosis in childhood, which partly informed her emotional relationship to diabetes. She also experienced a traumatic hypoglycemic episode a few years after her diagnosis, which resulted in seizures and hospitalization. This event made her so frightened of low blood sugar that she began letting her blood sugars run high.

D. Awareness of Mortality

Five of the nine participants (P3, P5, P6, P7, P8) expressed experiencing an increased awareness of mortality and identified this as a source of emotional labour. This increased awareness was linked with diabetes distress, and to cope with this distress and protect their mental health, participants had to expend emotional labour.

P7 articulated this heightened awareness of mortality as awe and fear at her dependency on modern technology, which she had only become aware of because of her diabetes. P8 noted that a single major disruption to supply chains and access to medical supplies could incapacitate insulin-dependent diabetics. P8 stressed, “I’m not suicidal. I’m not depressed. But it would be so much easier if I just didn’t have to deal with it. Can I just not for two days? [But] I know that two days would literally kill me.” This statement was compelling for two reasons. First, it demonstrated P8’s awareness of her mortality, the link between the absence of glycemic management and death. Second, she made a distinction between clinical depression and the distress that arises from the experience of living with diabetes—*diabetes distress* (Fisher et al., 2008; 2012). One facet of this distress is an increased awareness of mortality that results from ongoing glycemic management. Of the five participants, P8 articulated this hyperawareness most explicitly:

Every so often, you just get hit with [the realization that you’re] much closer to death at any given point. I feel like every so often, I just get reminded of my mortality in a way that I assume other people aren't dealing with—don't have to deal with.

However, P8 expressed that she was unable to dwell on whether she would experience diabetes complications, including death, one day. She acknowledged having a propensity for suppressing her feelings because she did not have the emotional bandwidth to invest labour in considering the long-term complications of her illness. This demonstrated the ways that emotional labour was finite resource, and that its over-expenditure increased distress.

E. Conceptualizing Difference

Four of the nine participants (P5, P6, P7, P8) reported expending emotional labour navigating how difference is conceptualized both within and outside of diabetes spaces, and how people with diabetes fit within other non-normative communities. Participants expressed feeling at odds with common, frequently positive rhetoric about diabetes and chronic illness

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more broadly (P5, P8). P5 expressed feeling that she was not like others and yet was surrounded by messaging that she was, and that she could accomplish anything she wanted. Resultantly, P5 felt that she *should* be able to do anything and that she was supposed to pursue her goals the same way any able-bodied person would. The discrepancy between this messaging and her lived reality created a deep sense of alienation and loneliness. These emotions, when coupled with an unwillingness to take care of herself, led to a nihilistic impulse: she felt there was no point to anything and struggled to form an identity that allowed for the inherent contradictions of living with diabetes. As a result, she felt that if she could not do everything an able-bodied person could, there was no point in doing anything at all. Furthermore, the popular refrain, “diabetes doesn’t define you,” increased feelings of alienation for P5. Internally, P5 did feel that diabetes has strongly shaped her relationship to herself and the world around her, so the pressure to create an identity outside of diabetes—especially for someone who has no memory of living without it—only compounded her loneliness and her struggle to form a positive self-identity. P5 emphasized that diabetes has strongly influenced the person she is at present.

P8 described being unable to relate to positive rhetoric about chronic illness and disability because she feels there is nothing positive about her diabetes. She commended activists for helping people with chronic conditions and disabilities overcome negative self-perceptions but expressed that it would be impossible for her to share this sentiment about herself: “I think [diabetes] only impacts my life negatively. I may have done cool things...but if I could give up all those things to not have diabetes, I would do that in a nanosecond.” For contrast, she highlighted how Deaf people share a culture, a language, and a community, and as a result, they do not have a strong desire to hear. Thus, Deafness can inform a positive self-concept, whereas for P8, diabetes informs a more negative self-concept.

F. Social Understandings of Healthy Bodies

Participants expressed grappling with social understandings of healthy bodies when trying to understand how diabetes informs their self-concept and their identity (P4, P7, P8). Because diabetes is an illness that carries social implications, participants expressed navigating and negotiating complex identities that were entangled in social and institutional structures responsible for producing ideas about non-normative bodies. These ideas go on to inform how people form their identity and their relationship to their body, which subsequently became a source of emotional labour for participants.

P8 self-identified as fat and disclosed feeling a great deal of distress whenever speaking to a dietician, which she attributed more to her weight than with diabetes, but the intersection of fatness and diabetes compounded her distress. When the topic of diet arose in a medical setting about diabetes, P8 simultaneously confronted social discourse around weight. Therefore, when P8 interacted with medical professionals who wanted to discuss her diabetes, she perceived a conversation about fatness. Processing the medical relationship to diabetes *and* the social and cultural relationship to fatness comprised a substantial expenditure of emotional labour, which also became woven into identity. P8's emotional labour was compounded because when made to address the medical, she could not extricate herself from the social dynamics of fatness, and this prevented her from being able to fully process or manage her diabetes to her standards:

Society has told me that fat people suck...But then maybe also if I wasn't so up in my head about people thinking badly of me because of being fat...I'd be able to be better at my diabetes.

P8 emphasized that her emotional labour was more wrapped up in her relationship to her weight than diabetes. However, the pain and emotional labour expended on the issue of

fatness arose in the context of diabetes care. Thus, P8's intrapersonal relationship to diabetes is informed by in the complex interplay between diabetes and fatness.

Conversely, P4 and P7 expressed not wanting to be perceived differently because of their diabetes. P7 reported not wanting to talk about diabetes even with friends, and P4 disclosed that her identity was informed by being a healthy person who took pride in being health conscious: "I really internalized ableism and healthism and felt that [diabetes] was going to change who I was and how people would see me." Thus, P4's diagnosis was so stressful partly because it uprooted an integral part of her identity. P4 and P7 further demonstrate how social, cultural, and institutional understandings about bodies and health impact identity for people with diabetes.

Theme 6: The "Bad Diabetic" and an Internalized Expectation of Perfect Control

An astounding commonality that emerged across interviews was the use of the term "bad diabetic" as a self-descriptor. Six of nine participants (P1, P2, P5, P6, P7, P9) independently used this term; seven of nine participants (P1, P2, P5, P6, P7, P8, P9) demonstrated strong attachment to the concept of "control" and linked their perceived level of glycemic control to their moods and sense of self-worth. Periods of perceived poor control were associated with guilt, shame, and worry, however, these feelings persisted even when control was perceived to be strong. The feeling that one is a "bad diabetic" appeared to have its origins in an internalized expectation of perfect control over one's glucose management. It is worth noting that all participants in this group except for P9 were diagnosed in childhood. For these juvenile patients, this expectation of control arose primarily from contending with impossible expectations imposed by the framework of diabetes education. Participants also emphasized feeling excessive personal responsibility for glycemic management, and this produced the belief that they are solely responsible for their health outcomes. As a result,

poor glycemic control, even in the short term, contributed to feeling like a “bad diabetic,” which impacted self-worth and created feelings of worry, shame, and guilt.

A. Impossible Expectations

Four participants (P1, P2, P5, P6) expressed that unrealistic expectations were imposed on them, and that the emphasis on numbers and “control” in diabetes education coloured their relationship to diabetes. Participants reported that these negative experiences contributed to feeling like a “bad diabetic” and set them up to internalize expectations of perfect control. Managing these internal dynamics and negative beliefs were required emotional labour.

Participants expressed that feeling like a “bad diabetic” endured into the present moment, despite having supportive care teams at present (P1, P6). Participants identified the origin of this feeling in their adolescence. For example, P1 recalled being told by her pediatric endocrinologist that she was a “bad patient” for not meeting expectations and believes this dynamic “did a lot of damage.” Her early antagonisms with her doctor not only prolonged her unreadiness to process the complexities of her illness but instilled in her a negative belief about herself that persists. This compounded the emotional labour that P1 expended, as it created additional stressors and complex intrapersonal negotiations that she navigated to maintain her mental health. When I asked P1 if she thought her feeling like a “bad diabetic” would ever go away, she replied:

I still feel like that little girl; that’s how she felt, and that’s how I’ve felt most of my life, so I don’t know. Those formative years might always be there, but I’m hopeful that...it will go away with time.

This emphasized the enduring impact of these early antagonisms with medical professionals and demonstrated the pervasive impact of the notion of “control” in diabetes management.

P5 expended substantial emotional labour as a child to convince her parents and her endocrinologist that she was “good” and that she was doing everything she could. If one must convince others of their goodness, then they implicitly view themselves as potentially bad. In recounting her reaction to unrealistic expectations, P6 said, “I just felt like, ‘Why bother? I feel like I’m already doing my best, and it’s not good enough.’” As with P1, medical settings, especially in pediatric care, contributed or instilled the belief that P6 was a “bad diabetic.”

Participants’ stories highlighted that unrealistic expectations rooted in a diabetes education that emphasized control created a catch22. P6 pointed out that young people with diabetes are asked to scrutinize their eating habits and are then scrutinized for overemphasizing the role of diet in their lives. She also criticized the application of conventional understandings of disordered eating to people with diabetes in the juvenile setting. She noted the impossible standard for people with diabetes to center numbers related to food in their quotidian while also maintaining a healthy relationship to food, explaining that it seems inevitable for young people with diabetes to develop disordered eating behaviours.

B. Emphasis on Personal Responsibility

Five of the nine participants (P2, P5, P7, P8, P9) revealed that feelings of personal responsibility for their glycemic management was a substantial emotional burden and source of emotional labour. Participants implied through their reflections on personal responsibility that they felt as though their health outcomes were the direct result of their glycemic management decisions. The alienating effects of living with diabetes and the idiosyncratic nature of the illness made it difficult to know if they were managing their illness “correctly,” while accounts of personal responsibility revolved around feeling like a “bad diabetic” and the internalized expectation of control.

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Participants disclosed feeling an enormous amount of responsibility for themselves, and this affected her mental health and well-being (P2, P5, P7). Both P5 and P7 acknowledged that even if they could replicate every aspect of a good day, those positive results would not necessarily be replicated, and P7 expressed frustration towards mishaps and negative outcomes. Nonetheless participants expressed struggling to shed the internalized belief that they can control external factors. P7 coped with this frustration by reminding herself that she has control in the present and can start over and work harder. However, this emphasis on trying harder and having control at present may feed an internalized expectation of total control and excessive responsibility, perpetuating the demand for emotional labour.

While P8 did not describe herself as a “bad diabetic,” she shared many of the features that informed this logic in other participants. Furthermore, she demonstrated a comparable belief that she is solely responsible for her health outcomes. Interestingly, the latter primarily revealed itself she talked about producing offspring. P8 indicated that she wanted children but felt that she should not have them because she does not want to “voluntarily” give someone diabetes: “I’d be like, ‘Oh, this is my fault.’ Any other disability, and I’d be like, ‘Well, that’s just how genetics work.’ But diabetes—I gave it to them. Why did I make this choice?” This revealed the extent to which P8 internalized the belief that she is solely responsible for the outcomes of her illness. Here, the potential of having offspring who develop diabetes was treated as a health outcome that arises from what was perceived as the parent’s voluntary choice. The health outcomes of the child, then, were treated as an indicator of the parent’s level of control, which in turn becomes a value judgment on the parent. The role of genetics—something that is outside the parent’s control—was deemed irrelevant because of the mere possibility of diabetes being passed on. Thus, the role of external factors was minimized while the role of volition was overemphasized. P8 indicated that she viewed diabetes as an imposition and as something that has only impacted her life negatively, so it

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was her imperative not to pass the illness on to her offspring, reflecting her feelings of personal responsibility around diabetes.

P8 also pointed out that diabetes is not an illness that “breeds solidarity,” which intensified feelings of individual responsibility: “I have no way of knowing how other people deal with [diabetes], and so you’re always going to think you’re bad because you don’t have a baseline.” She noted that because diabetes management is so idiosyncratic, there was not much reason for people with the illness to draw together. P8 thus understood diabetes as an atomizing illness that is both alienating and amplifies feelings of personal responsibility for health outcomes, which in turn makes people feel as though they are “bad diabetics.”

P9 also expressed feeling like a “bad diabetic,” which arose from guilt that she was not doing enough to manage her diabetes. She indicated that her impulse to compare herself to other T1s intensified feelings of personal responsibility: “Maybe I’m a bad diabetic. I’m not taking enough insulin, or I don’t exercise enough, or [I’m] not diligent enough.” P9 elaborated that diabetes is not like other chronic illnesses in which treatment is *given* to a patient. Rather, the person with diabetes oversees their own treatments and self-administers, which for P9 contributed to the idea that “if you were more diligent, your treatment would be more effective.” P9 identified managing and processing this dynamic as a huge source of emotional labour. Furthermore, she expressed that diabetes forced her to “live in [a] kind of middle ground...you have this responsibility all the time.” P9 believed that diabetes imposed greater expectations on the individual and articulated that if people with diabetes behaved like others, they would “pay” with the consequences. Thus, negative consequences reflected an apparent failure to take responsibility for one’s health, which in turn fueled the belief that one is a “bad diabetic.”

C. Glycemic Control = Self-Worth

Those who identified as “bad diabetics” struggled with self-worth when they felt their glycemic control was not ideal. Participants indicated that their best and worst days revolved around diabetes (P1, P2, P5), describing their best days as those in which their blood sugars were “in range” or “under control.” Conversely, when they were struggling with glycemic control, their sense of self-worth was challenged. Processing and coping with these dips in self-regard was identified as a source of emotional labour.

P1 repeatedly emphasized the word “control,” which appeared to be ingrained in assumptions about what diabetes management should look like. When I asked what her worst diabetes days looked like, she said:

...days [when] you don’t expect anything to go wrong, but then something just fails, and it completely dominates your day. [It] makes me feel like I’m out of control, or not that I’m out of control, but I don’t have the ultimate control.

Participants placed importance on helping others or giving back to the community as a strategy to combat the negative impacts of living with diabetes (P1, P2). Helping others through charity and advocacy was a vehicle through which participants exercised control over diabetes and assert agency, which improved self-worth (P1, P2).

Importantly, P2 revealed that she had never had an HbA_{1c} over 7.4%¹, yet she is still burdened by feelings of isolation and unhappiness, suggesting that strong glycemic management may not decrease emotional labour and diabetes-related distress. When P2 revealed feeling burdened despite excellent glycemic control, I asked her how this impacted her. She told me, “It makes you feel like you’re never good enough. You come back with a

¹ Most diabetes associations and endocrinologists will ask patients to aim for an HbA_{1c} around or below 7% (Diabetes Canada). However, in the elderly, an HbA_{1c} between 7-8% is understood to be ideal, as the risks of lower A_{1c}s outweigh the benefits (Meneilly et al., 2018, p. S284)

95%, and the response isn't, 'phenomenal job,' the response is, 'tell me which questions you missed.'"

Participants attached their self-worth to numbers and found it difficult to view numbers as value-free, which exacerbated the need for perfect control (P1, P2, P5). This mindset towards diabetes rippled out to other aspects of their lives and impacted self-worth and quality of life:

My whole life is numbers, whether it's measuring carbs, measuring insulin, looking at my HbA_{1c}. Every single action that I do, I'm judged by a panel of people that are giving me numbers, and I'm defined by those numbers... You turn on your data to look at it over time, and you feel like you are those numbers, and you're nothing more (P5).

P5's disclosed that her moods directly reflected her blood glucose levels, and she expressed feeling undeserving of a positive status quo. She reported struggling to maintain a stable emotional state because she had internalized the belief that her blood glucose results were a direct measure of her self-worth. Consequently, her moods swung between extremes, and she experienced anxiety attacks. This, she said, was a major source of emotional labour that required (and continues to require) constant work and vigilance.

D. Shame, Guilt, and Worry

Five participants (P1, P2, P5, P7, and P9) expressed feeling shame, guilt, and worry about their glycemic management, and this appeared to be irrespective of how strong that management was. The internalized expectation for control and excessive feelings of personal responsibility produced feelings of shame, guilt, and worry in moments when participants felt their control was slipping, even if temporarily. Furthermore, guilt, shame, and worry that arose during moments of perceived poor control persisted into periods of strong control, and

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grappling with this lasting impact, as well as the initial emotional reaction, was identified as a source of emotional labour.

Lack of control was associated with guilt and shame (P1, P2). P1 articulated understanding that energy is finite but nonetheless felt guilt for prioritizing anything except her glycemic management. Subsequently managing that guilt and deconstructing why it arose constituted emotional labour for her. P1 attempted to offset her guilt by donating to organizations that recycle old diabetes supplies. The source of her guilt was her failure to capitalize on her privilege: due to her access to supplies, she felt that any slippage in her glycemic control constituted a failure to appreciate the supplies and medical interventions to which she had. Her implicit belief was that access to resources negated any excuse not to attain perfect glycemic control. However, by making a positive impact on others and redistributing resources, P1 blunted the negative emotional impact of less-than-ideal glycemic control and the shame and guilt it produced.

Participants also likened diabetes to worrying about a test result (P2, P5, P7). The emphasis on testing has created a fraught relationship to health, eliciting a great deal of anxiety. P7 reported frequently asking herself, “What’s next?” as though expecting negative outcomes as an eventuality. This is in part the result of frequent blood tests, and she reported struggling to disconnect her general health issues from diabetes.

Participants described experiencing health anxiety around appointments and blood tests (P6, P7). Because good control does not guarantee an absence of complications, persistent anxiety before appointments was common. Furthermore, feelings of being a “bad diabetic” intensified this fear. Participants also reported awareness that their actions have limited impact, and that bad things can happen irrespective of their choices. The degree of diabetes distress and health anxiety experienced by participants produced an additional demand for emotional

labour, which they invested in managing and processing feelings to try and restore an emotional equilibrium.

Chapter 6. Discussion

Through this thesis I explored the experiences of young adults living with T1 diabetes and have provided extensive analysis of participant-identified sources of emotional labour. Although I have broadly categorized these sources using seven themes, I wish to allocate discussion space to addressing three major points of consideration: mental health, ableism and social understandings of health and illness, and finally, a philosophical reconsideration of optimism and futility, which has strong implications for praxis and diabetes education.

Mental Health

Current research on T1 diabetes and mental health has demonstrated increased incidence of psychological distress, mental health challenges, and stigmatization. Ferro (2016) concluded that “lifetime prevalence of mental disorder was significantly higher for individuals with chronic health conditions compared with healthy controls,” and that “physical and mental comorbidity is prevalent among emerging adults” (p. 462). Furthermore, the 2018 Diabetes Canada Clinical Practice Guidelines for diabetes and mental health—the most recent of its kind—indicated a 30% prevalence of depressive symptoms and twice as much major depressive disorder (10%) compared to other chronic illnesses. Furthermore, the risk of experiencing depression was found to increase with the duration of illness. Diabetes diagnosis was associated with a doubling of antidepressant prescriptions, where undiagnosed diabetes was not, suggesting that the depression is linked to aspects of diabetes management (Robinson, et al., 2018, p. S131). Furthermore, depressive episodes were more likely to last longer and recur in people with diabetes. Anxiety was reported as comorbid with depressive symptoms, with one study showing that approximately 14% of patients with diabetes struggled with generalized anxiety disorder; 28% suffered from subclinical anxiety disorder, and 42% reported experiencing some anxiety symptoms (Robinson, et al., 2018, p. S133). It is further accepted that eating attitudes and behaviours

defined as subclinical are almost twice as prevalent in young women with diabetes compared with non-diabetic controls (Goncalves et al., 2016). Chelvanayagam and James (2018) have noted that research indicates that up to 20% of women with T1 diabetes struggle with diabulimia.

My research on emotional labour strongly suggests that young adults with T1 diabetes struggle with feelings of social alienation, shame, guilt, and challenges to self-worth. Depression and anxiety arose as multiple times during interviews, supporting the existing literature on mental health and diabetes. However, much of the literature treats mental health complications as being incidental or comorbid to diabetes. Important strides have been made with the notion of diabetes distress (Polonsky et al., 2005; Fisher and Polonsky et al., 2012), which re-conceptualizes the relationship between diabetes and mental health complications by suggesting that mental health complications arise as a natural consequence of ongoing diabetes management. However, while diabetes distress asserts an important relationship between diabetes and mental health challenges, it does not account for *how* and *why* diabetes spurs such intense distress. My research fills this gap in the literature by offering further insight into diabetes distress via emotional labour.

Recalling that diabetes distress arises specifically as a response to a life-changing illness and is distinct from depression in that it is rooted in “the demands of diabetes management” (Berry et al., 2015, p. 278), compelling accounts from participants suggest that diabetes distress may arise in response to the demand for emotional labour, and diabetes distress may incite a further demand for emotional labour to process said distress. Thus, the relationship between diabetes distress and the over expenditure of emotional labour may be somewhat cyclical and mutually reinforcing: the very act of diabetes management gives rise to negative emotions, which require emotional labour to process. However, the expenditure of emotional labour, or constantly being “on,” as one participant described, may produce or

increase diabetes distress, and this distress, in order to be processed, navigated, and coped with, requires the further expenditure of emotional labour.

It is also important to note that emotional labour does not arise solely from the material and mechanical demands of diabetes management. Participants identified specific aspects of living with diabetes more broadly as sources of emotional labour, and the over-expenditure of emotional labour was heavily associated with managing external stressors that challenged participants' mental health. In Kelly et al. (2019), emotional labour functioned as a "disengagement coping mechanism" when over-expended, meaning that individuals tended to distance themselves from the stressor (p. 3). This emerged as a serious challenge for participants in my study, who often disengaged from stressors related to their diabetes, including complicated dynamics with family, friends, romantic partners, and healthcare providers. Furthermore, the over-expenditure of emotional labour in navigating these external dynamics contributed to participants internalizing negative beliefs about themselves and their diabetes. This increased feelings of distress, anxiety, shame, guilt, and alienation. In turn, these feelings, which were especially prevalent in participants' memories of adolescence, increased disengagement tactics such as avoidance, denial, and dishonesty.

Even in adulthood, most juvenile-onset participants reported struggling with feelings of shame, guilt, and alienation that initially arose in childhood or adolescence, and these feelings persisted irrespective of their current glycemic control and relationships. The persistence of negative beliefs about oneself, stemming from early antagonisms with family and healthcare providers especially, suggests that there is a high degree of vulnerability and impressionability in adolescence. Thus, fraught or distrusting relationships with medical professionals and family appear to have long-term implications for the emotional well-being of the patient.

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Furthermore, participants highlighted that their experience of living with diabetes was incommensurable with their friends', families', and intimate partners' experience of the participant's diabetes. This created an alienating effect on participants, which in turn had negative consequences for their mental health and capacity for glycemic management. Participants also demonstrated a tendency to expend disproportionate amounts of emotional labour to mitigate conflict in close relationships, and this was usually accomplished by preserving the comfort of the other party or by protecting them from negative feelings. Participants felt they needed to perform "mental calculus" to decide how to respond to others, and this often happened in conjunction with pressure to over-empathize to protect others' feelings. However, this often came at the expense of the emotional wellbeing of the person with diabetes, which resulted in a loss of capacity for diabetes management.

It is worth noting that "mental calculus" is closer to what Hochschild (2012) calls cognitive labour rather than emotional labour. While both Hochschild (2012) and I made a theoretical distinction between emotional labour and cognitive labour, it was evident that participants perceived the two as being highly entangled. For example, mental calculus (cognitive labour) elicited emotional labour in that it was driven by a perceived obligation to empathize with and protect the feelings of hegemonic groups (emotional labour). Therefore, it may be the case that cognitive labour acts as an internal stressor that both produces and is motivated by a demand for emotional labour. Furthermore, relationships in which the person with diabetes expended disproportionate amounts of emotional labour appeared to have a negative impact on self-esteem and the individual's intrapersonal relationship to diabetes. Participants also showed a tendency to structure their approach to relationships around diabetes, as they implicitly understood diabetes to be a potential wedge in their relationships.

The aforementioned dynamics suggest that people with diabetes experience a kind of doubling of responsibility. Not only are they understood to be solely responsible for the

outcomes of their illness (a belief they often internalize), but they frequently became responsible for managing others as well. Based on participant accounts, I observed a failure on the part of family, friends, laypeople, and healthcare professionals to understand that people with diabetes do not exist and make choices in isolation but are beholden to social dynamics and medical regimes they frequently have little control over. This was compounded for participants while they were minors, who are legally disempowered. For one participant, this meant that her mother did not allow her to speak with her doctors alone, making it difficult for the participant to attain information that would have spared her distress and potentially helped her make responsible decisions. For many participants, parents often held an unrealistic expectation that their child ought to “get their act together” while making no effort to interrogate their own contributions to the child’s self-destructive behaviour.

Furthermore, according to participants, parents seemed unaware of their tendency to make their child responsible for managing parents’ negative emotions. Based on interviews with participants it appears that parents of chronically ill children, where the chronic illness requires constant management, are not always equipped to manage their own emotions while supporting their child. As a result, the parents do not know how to set healthy boundaries with a child that is being self-destructive, and this can lead to continuous strain in the relationship, excessive policing and intrusiveness in the child’s life, and erosion of trust. These parenting approaches are similar to authoritarian parenting, which is described as coupling “low level of responsiveness with high demandingness and is known for its highly structured, rule-based approach with minimal focus on warmth and emotional support” (Noser et al., 2018, p. 1316). Thus, policing behaviour and intrusiveness can be understood as a facet of authoritarian parenting. Unfortunately, such critical parenting styles have been linked to elevated diabetes distress, parent-child conflict, and diabetes management more broadly (p. 1316). Thus, children with diabetes must expend emotional labour to understand

where and why the family dynamic is deteriorating and establish boundaries that will protect both the child's and the parents' mental health. These dynamics produced in participants a tendency towards excessive responsibility for their health and relationship outcomes, and the atomizing impact of this tendency compounded mental health struggles such as depression, anxiety, feelings of guilt, shame, and worry. Importantly, problematic dynamics that exist independently of diabetes were made more visible and exacerbated by diabetes, thus creating a demand for greater expenditure of emotional labour for the person with diabetes.

Another facet of the failure to recognize people with diabetes as entangled parties in a web of social relations is how medical non-adherence or poor glycemic control is understood. There appeared to be a widespread belief among family, friends, and healthcare providers alike that poor glycemic control was a deliberate act of self-sabotage or resulted from lack of effort. In response, family, friends, and healthcare providers showed a tendency to resort to anger, fearmongering, guilt, shaming, and reminding participants of the potential for diabetes complications to try and motivate stronger glycemic management. The idea that knowledge of consequences should modify behaviour appears to be a key assumption that many family, friends, laypeople, and healthcare providers hold, and this compounds emotional labour for people with diabetes, as they feel they must justify themselves to validate the perspective that people will act rationally once they have knowledge of the consequences.

These interactions then become a source of shame, as the perception of being a “bad diabetic” can stem from feeling judged for knowing the consequences of high blood glucose but failing to control it nonetheless. Although not an exact equivalence, these perceptions of being a “bad diabetic,” fear of judgment, and tension in interpersonal relationships resulting from poor glycemic management appear to be characteristic of diabetes distress, which Robinson et al. (2018) define as “the despondency and emotional turmoil specifically related

to the need for continual monitoring and treatment, persistent concerns about complications, and the potential erosion of personal and professional relationships” (p. 130). It is possible, then, that the notion of feeling like a “bad diabetic” occurs simultaneous to diabetes distress. When understood in tandem with my findings, diabetes distress, may be a phenomenon that is spurred by social dynamics (including those in medical settings) more so than previously acknowledged.

Furthermore, failure to control blood glucose in spite of knowing the consequences becomes perceived by healthcare professionals as belligerently poor decision-making, when the reasons behind the behaviour are likely more complex. These beliefs on the part of healthcare providers and the patient’s family, friends, and acquaintances come to characterize the ethos of the patient’s primary support systems. Because these beliefs are inherently negative and convey a lack of compassion, they negatively impact the person with diabetes, who may then resort to more disengagement tactics as a self-protective measure. This is similar to observations made by Kelly et al. (2019) regarding racial marginalization. When over-expended, emotional labour functioned as a disengagement coping mechanism for black women in traditionally white universities (p. 3). Kelly et al. (2019) further noted that disengagement coping mechanisms are more common in people with marginalized identities, which can include race, gender, sexuality (p. 3), and, in the instance of my research, chronic illness. Disengagement coping strategies have been shown to worsen psycho-social outcomes (Dijkstra and Homan, 2016). Interestingly, parents of children with chronic illnesses are prone to disengagement coping mechanisms (Cousino and Hazen, 2013; Rabineau, Mabe and Vega, 2008), and Waugh et al. (2021) noted that avoidance specifically represented a maladaptive coping mechanism (p. 220-221). For participants in my study, disengagement also compounded social alienation and feelings of shame, guilt, and worry. This may further contribute to the aforementioned cycle of diabetes distress and emotional labour.

Altogether, these findings about the dynamics of mental health challenges faced by participants highlights the importance of recognizing how and why diabetes distress manifests and how it both produces and is produced by an over-expenditure of emotional labour. Although participants expressed a diversity of experiences with diabetes that elicited or compounded mental health challenges, which in turn required emotional labour to process and manage, some common threads emerged. Participants identified extreme glycemic variation as a source of distress and subsequent emotional labour. The physical manifestations and complications of the illness were understood to incite negative emotions, which then required an expenditure of emotional labour. Furthermore, the constant and unyielding presence of diabetes in all facets of life was a source of mental health challenges that subsequently require emotional labour for participants to process.

Interestingly, even when diabetes was not made central, as is the case with many adolescents, emotional labour was still expended on negative coping mechanisms such as denial, disengagement, and suppression. Thus, participants reported feeling diabetes burnout, depression, and anxiety even when they were ostensibly not putting effort into mechanical diabetes management. This suggests that their emotional resources and emotional labour were nonetheless being expended on diabetes—namely, coping (sometimes ineffectively) with negative emotions and distress that arose from the illness. Participants indicated that diabetes also produces a more intense awareness of mortality and dependency on social and institutional structures—something that has not yet been explored in existing literature on diabetes. This awareness produces conditions for anxiety and distress to flourish, which then requires that people with diabetes expend emotional labour to cope with and process these broader existential anxieties. Overall, complex social negotiations and relationship dynamics were a strong contributing factor to mental health challenges that compounded emotional labour.

Ableism and Social Understandings of Health and Illness

During my interviews, it became clear that social understandings of health and wellness profoundly impacted participants, particularly in how they formed their identities, their relationship to their diabetes, and the way they navigated social spaces. Social understandings of chronic illness, which are unfortunately steeped in ableist logic, impact the interpersonal, professional, medical, and casual relationships of people with diabetes. Furthermore, discourse on dis/ability has proven to be a fraught topic for people with diabetes, who may be unsure of how they fit within this discourse and disability spaces. Moreover, people with diabetes are not immune to internalizing conventional social understandings of health and illness, which favour an ableist impulse.

Dan Goodley's theoretical framework of ableism in *Dis/ability Studies* (2014), summarized in a review by Hewlett (2021), asserts that ableism "privileges the ideal image of an autonomous, independent, fully able-bodied, and productive individual while 'othering' people or groups that do not conform to those exacting standards" (Hewlett, 2021). How well people with diabetes fit this framework of the able-bodied individual was a common theme in my interviews, and participants often expressed not being able to arrive at clear answers. Rather, they felt their position within this framework was tenuous, frequently leaving them in a liminal space that I have called conditional able-bodiedness. However, the ways in which people with diabetes do experience disability profoundly impacted all facets of their lives.

Jeong et al. (2018) identified five themes impacting perceptions of stigma among people with T1 diabetes: (a) Desire to be Seen as a Person, Not a Disease; (b) Wanting to be "Normal"; (c) Feeling Ashamed Managing Diabetes in Public; (d) Struggling to Overcome Anger and Distress; and (e) Feeling Distrusted by Others to Manage Their Condition (Jeong et al., 2018, p. 44). The participants reported a "high degree of stigma in their daily lives, which negatively influenced...psychological well-being [and] led to...feelings of anger and

distress” (Jeong et al., 2018, p. 44). The themes highlighted by Jeong et al. (2018), specifically, shame managing diabetes in public, being seen as a disease rather than a person, and wanting to be “normal,” suggest that people with diabetes contend with ableist social understandings of their illness. My research with emotional labour supports the findings of Jeong et al. (2018) and expands upon them by providing a detailed analysis of how, precisely, people with diabetes navigate ableism by over-expending emotional labour.

One profound example of this ableism is how accommodations are understood in the workplace. P7’s fear of being seen as someone who will demand accommodations suggests that her workplace does not understand accommodations as something that help workers perform their jobs better, but rather, as something that reveals an inability to do those jobs. Therefore, the notion of accommodations in relation to P7’s diabetes created a demand for emotional labour as P7 attempted to prove that her illness was not a hindrance to her ability to perform her job. Unfortunately, this suggests that workplaces may perpetuate the idea that they do not owe their employees accommodations, which is a cornerstone of ableist thinking in that it privileges the “autonomous, independent, fully able-bodied, and productive individual” while othering those who are unable to “conform to those standards” (Hewlett, 2021). It also demonstrates how conventional understandings of workplace culture, which employ this ableist logic, can be internalized by people with disabilities and chronic illnesses, who then feel pressured to prove their productivity. This adds yet another layer of emotional labour to quotidian. Rather than expressing her needs, P7 expended emotional labour worrying over the potential consequences of expressing those needs.

Ableism also featured prominently in how participants navigated relationships. Participants expended emotional labour to minimize their interactions with ableist thinking, or, in some cases, pre-empt or correct it. Despite taking different approaches, participants had to expend emotional labour. For example, P3 used disclosure as a tool to filter out ableist

partners because she did not want people to leave her once they found out she has diabetes. This approach revealed an implicit recognition that diabetes is a detriment in her personal relationships, and this recognition was rooted in personal experience with previous partners. Helgeson (2017) demonstrated that partner under-involvement in diabetes care was linked to poorer diabetes outcomes (p. 215). In P3's case, partner under-involvement or abandonment (perhaps the most extreme manifestation of under-involvement) appeared rooted in ableist thinking and motivated her to shift her approach to romantic relationships. As a result, her approach to personal relationships required her to expend emotional labour to maneuver around ableist thinking. Conversely, P4 took the opposite approach and withheld her diabetes diagnosis upon an initial meeting to try and encourage people to see her as more than just her illness. P4 did not wish for a chronic illness to be one of her defining features in her romantic relationships. However, this implicitly positioned diabetes as undesirable; her reluctance to disclose her illness, coupled with her strong resonance with health, still tacitly acknowledged the view of her illness as socially undesirable. Her emotional labour, then, while protective of her own mental health, also protected the ableist understanding of diabetes, and she invested her emotional resources to convince others that she is, in Hewlett's words, "an autonomous, independent, fully able-bodied, and productive individual."

This is not to suggest that P4's relationship with diabetes was incorrect or needing adjustment, but rather, to highlight the complex ways in which the demands for social negotiation and intrapersonal negotiation create the conditions that result in high levels of emotional labour. Similarly, while P3 minimized potentially wasted emotional investment in people by being upfront about her illness, this impetus for self-identification was the result of her awareness that there are people who *will* choose not to form relationships with her because of her diabetes. Thus, P3's approach did not actually blunt the reality that she was impacted by other people's ableism; it merely re-directed the emotional labour inward and

forced her to contend with the subtler impacts of self-identification: that her illness was still a determinant in her interpersonal relationships. She was foreclosing social possibilities in the interest of protecting herself and her time investment, yet in doing so, her social landscape conformed to an expectation of emotional labour.

P7 and P9 also expressed a preference for keeping their illness as invisible as possible and minimizing the degree to which others had to interact with it. According to Goodley (2014), ableism privileges a standard of bodily normativity that renders those who do not meet it as ‘other.’ The very fact that people with diabetes feel compelled to either hide their illness or use it as a disclaimer suggests a recognition that diabetes others them, revealing that social understandings of diabetes, and chronic illness more broadly, remain laden with ableist thinking. These impulses further suggest that in hegemonic spaces, isolation and alienation may be ordinary for people with diabetes because they are always being measured against a standard of normativity they cannot meet. It was clear from interviews that people with diabetes often assume they are the minority in most spaces. Participants showed discomfort with the interplay between their illness and public perceptions of their illness, leading them to expend emotional labour either to educate laypeople or to minimize the visibility of diabetes for laypeople’s comfort.

Another complicated facet of social perceptions of diabetes is highlighted in the defensiveness people with T1 diabetes feel when they are mistaken for having type 2 diabetes. Jeong et al. (2018) identified that the conflation of T1 and type 2 diabetes was a source of social stigma for people with T1 diabetes, though the study does not delve into the reason why people with T1 diabetes feel stigmatized by the conflation. My study expands upon Jeong et al. (2018) by providing insight into how and why this stigma is felt.

Furthermore, I demonstrate that managing this stigma is a source of emotional labour for people with T1 diabetes. The unspoken assumption underlying the aforementioned social

stigma is that type 2 diabetes has negative social connotations, thus, being understood as a type 2 diabetic extends that social stigma to people with T1 diabetes. However, people with T1 diabetes are not immune to internalizing negative beliefs about type 2 diabetes. T1 defensiveness around being mistaken for a type 2 typically results from the association between type 2 diabetes and poor lifestyle choices. However, the long-standing belief that poor lifestyle choices *cause* type 2 diabetes is rooted in two logical fallacies: first, the post hoc fallacy, which confuses correlation for causation, and second, the fallacy of division, which mistakenly applies generalizable findings (i.e., unhealthy diet and lack of exercise are a risk factor for metabolic diseases) to individual instances in which causation is often impossible to identify. Thus, the belief that people with type 2 diabetes are categorically irresponsible with their health is untrue but persists due to ableist frameworks that position the individual as the sole agent in all their health outcomes.

Unfortunately, many people with T1 diabetes may internalize the idea that their health outcomes are their sole responsibility, and that they must make all the correct choices to control those outcomes. Thus, rather than correcting the association between type 2 diabetes and poor lifestyle choices, they may become defensive and defend their personal circumstances instead. Rather than interrogating why the conflation of T1 and type 2 diabetes creates negative feelings, people with T1 diabetes may also contribute to the moral division between T1 and type 2. This results in additional stigma for type 2s and for T1s who have “markers” of type 2 diabetes, such as a larger body.

Ableist frameworks and attempts to dismantle them may also create complex relations and associations to disability and able-bodiedness for people with diabetes. Participants indicated that how they form their identities and see themselves in both normative and disability spaces was impacted by these ableist frameworks. Research on how diabetes fits existing discourse on disability is wanting, however, this study implies that people with

diabetes struggle to place themselves within this discourse. Participants identified grappling with notions of disability and able-bodiedness as a source of emotional labour. Because people with diabetes exist outside of conceptions of the normative body, they must also contend more intensely with social, cultural, and institutional understandings of health, which sometimes prove reductive. For example, while P8, P4, and P7 demonstrated different relationships to social messaging about non-normative bodies, they each expressed struggling with the same problem: how to form an identity while juggling both diabetes and reductive understandings of healthy bodies. Despite relating to social messaging about healthy bodies differently, these participants share the same marginalization: diabetes. Thus, because of their marginalization, they must expend emotional labour to tease apart how they fit in a social and cultural context that, according to Goodley (2014), does not always make space for people with disabilities, chronic illnesses, and conditional able-bodiedness. P8, P4, and P7 are also excellent examples of the fact that communities who share the same identifier (i.e., diabetes) are not a monolith and can form very different individual identities.

Regardless of how participants understood their identity in relation to diabetes, they all acknowledged—either tacitly or explicitly—that diabetes provoked self-reflexivity and demanded they expend emotional labour to understand, conceptualize, or re-conceptualize identity. Furthermore, it became evident that identity, even when fluid, can sometimes be uncomfortable for people with diabetes because, as participants indicated, it is frequently illegible to those who do not live with the condition. For this reason, feeling “seen” presents a challenge for people with diabetes, and they must frequently expend emotional labour to make their identities legible to others. Importantly, identity does not exist in a vacuum, and the narratives presented by participants demonstrate the degree to which identity is informed not only by personal circumstances (i.e., living with diabetes) but by a broader socio-cultural context that ascribes meaning to and produces knowledges about those personal

circumstances (i.e., ableist notions of chronic illness). Interviews with participants showed that navigating these meanings and knowledge productions about diabetes ultimately falls on people who live with the condition. As qualitative research on living with diabetes is scarce, such stressors on people with diabetes are broadly unacknowledged and consequently unexamined. Therefore, to maintain a healthy self-concept in the context of these broader epistemologies, people with diabetes must expend disproportionate amounts of emotional labour compared to the general population.

Finally, interactions with the healthcare system and government bureaucracies revealed the extent to which ableist frameworks pervade government and healthcare institutions. It was evident from interviews that a person with diabetes may expend disproportionate amounts of emotional labour compared to the general population when forming and maintaining relationships with healthcare providers. Due to the chronic nature of the illness, people with diabetes tend to require more preventative care from a variety of medical fields, such as bi-annual or quarterly bloodwork, cardiology, and ophthalmology, when compared to the general population (Poirier et al., 2018; Altomare et al., 2018; Berard et al., 2019). As a result, they are more likely to expend their emotional labour in these capacities more often than someone without diabetes. Unfortunately, this means navigating ableist assumptions within healthcare more often. Participants reported encountering presumption, hurtful or inappropriate comments, and lack of empathy from healthcare providers. These experiences stemmed from ableist assumptions about what constitutes a life of thriving and the aforementioned belief that the patient is solely responsible for their health outcomes. Lack of empathy in particular stuck with participants and evoked feelings of powerlessness and invisibility by the very support systems meant to help them. Importantly, lack of empathy is hardly a trivial matter in healthcare. Citing Del Canale et al. (2012), Dr. Danielle Ofri, MD writes:

In one of the largest studies of its type, more than 20,000 diabetic patients of 242 doctors were analyzed for the severest swings of glucose—the type of hyper- and hypoglycemia that leads to hospitalization and coma. The doctors all took the JSE empathy test and were divided into groups with high, moderate, or low scores. The rate of severe diabetes complications in patients of high-empathy doctors was 40 percent lower than that of patients with low-empathy doctors. This is comparable to the benefits seen with the most intensive medical therapy for diabetes, except that those treatments also cause significant side effects. (So far, there haven't been any documented “adverse outcomes” in patients treated by highly empathic doctors.) (Ofri, 2013, p. 83)

Additionally, participants lambasted bureaucratic barriers that prevented them from receiving devices or treatment unless they “jumped through hoops” or demonstrated arbitrary compliance, a problem that has been theorized about at length in humanities disciplines. For example, Michel Foucault's seminal concept, biopower, explored in *Discipline and Punish* (1977) and *The Birth of Biopolitics* (1979), describes the institutional regulation of human life both on an individual and population level. Biopower has two major components: disciplinary power, which produces what Foucault called “docile bodies” that can be “subjected, used, transformed, and improved” (Foucault, 1977, p. 136), and second, through biopolitical power, which attempts to “optimize” the life of the broader population. Together, these components allow the state to separate people into the categories of “normal bodies” and “abnormal bodies.” Altogether, biopower is a tool that allows the state to secure an able-bodied population that is more or less self-regulating (i.e., preventative medicine is a form of biopower, and the self-regulating subject seeks out preventative medicine as they are educated to do). However, for those with chronic illness, biopower is particularly restrictive

as it demands more of them to perform able-bodied functionality even as a prerequisite for attaining needed medical devices for their chronic illness.

My interviews revealed this Foucauldian theory in action, as people with chronic illnesses are classified as having “abnormal bodies,” and to receive accommodations from the state, they must prove that they are able and willing to invest in disease management to bring their body’s functionality as close to normativity as possible. Government bodies ostensibly add a new layer of pressure on patients to perform compliance and demonstrate that they are worth the government’s investment in their health. Those who do not are presumably left to flounder, while those who do must continuously expend their emotional labour to maintain their performance. This kind of institutional appraisal of compliance classifies patients as “good diabetics” and “bad diabetics,” which not only impacts patients’ view of themselves and their relationship to their illness, but it also prevents them from receiving treatments and devices that may improve their glycemic control.

The bureaucratic and institutional barriers highlighted by participants exemplified how the state can create additional labour by holding medical equipment hostage unless the patient performs a certain way. Furthermore, there is pressure on juvenile patients to demonstrate more vigilance around their diabetes care than is expected of adult patients. Given that adolescence and young adulthood are already tumultuous periods, the additional pressure make diabetes omnipresent via devices such as pumps and continuous glucose monitors (CGMs) creates further circumstances in which patients must expend emotional labour. Such bureaucratic and institutional barriers also exemplify a profoundly ableist framework: if patients cannot perform normativity to a particular standard and wrangle their bodies into normative, able-bodied functioning, then they are deemed poor self-regulating subjects who are excluded from social contract on the basis of their failure to be “autonomous, independent, fully able-bodied, and productive individual[s]” (Hewlett, 2021).

Social understandings of healthy bodies have implications for both access to devices and care and how people with diabetes navigate employment. They also present particular difficulties for interpersonal relationships and navigating identity formation. The demands to perform being able-bodied to be accepted within a normative framework while simultaneously being made to “prove” disability and medical compliance generates a tenuous relationship to the chronic illness; one is both constantly downplaying the impacts of the illness to avoid ableism but also socially and institutionally never permitted to exist outside of it.

A Philosophical Reconsideration of the Roles of Optimism and Futility

In my interviews, one of the most profound sources of emotional labour and suffering came in tandem with the belief that one is a “bad diabetic.” This belief appeared to stem from an unfortunate confluence of various factors: diabetes education, an emphasis on personal responsibility, and the impact of glycemic control on self-worth, to name a few. All these intersected at an internalized expectation of perfect control.

I noted that the internalized pressure to have perfect glycemic control created a demand for emotional labour, as the person must navigate complex emotions that arise when control inevitably falters. However, this emotional labour is compounded by the ways internalized expectations of control and external expectations of control intersect. The concept of control appears discursively ingrained in how both medical professionals and patients talk about diabetes and diabetes education. “Control” becomes a cornerstone of compliance and diabetes management; thus, any deviation from this foundational assumption about management can leave a patient feeling out of control, which informs perceptions of being a “bad diabetic.”

Participants’ comments revealed that the way people with diabetes interact with their illness is through the idea of “control,” which becomes the lingua franca of diabetes in

healthcare, in diabetes communities, and internal to the person with diabetes. However, in other disability communities, there is no pressure to “control” the disability. People with deafness cannot control their deafness; they develop different ways of interacting and communicating intrapersonally, interpersonally, and socially. However, people with diabetes are trained to interact with themselves and others via the notion of control, which creates a highly atomizing and individualized experience because no two people can have the same experience of “control.” Thus, it is impossible to have a common experience through the language of control. Furthermore, because blood glucose testing and HbA_{1c}s become a measure of the individual’s success in managing their illness, comparison between people with diabetes becomes an inevitability, and this comparison becomes the cornerstone of feeling like a “bad diabetic” who lacks control.

Furthermore, participants related diabetes management to taking a test and reported feeling shame, guilt, and worry about their management even when it was strong. The feeling of “not being good enough” may be pervasive for people with diabetes precisely because there is no point at which the task of management is complete. Unlike a school test, which ends once the test is graded, diabetes is a series of micro-tests that continue throughout life, and there is no definitive evaluation for what constitutes a “good grade.” As a result, one can never “pass” the test with any finality; rather, it is an exercise in futility: people with diabetes must pass an infinite number of tests with shifting criteria until eventually they fail one of them.

This feeling of futility was shared by multiple participants and also appears to arise from an increased awareness of mortality and the knowledge that diabetes complications can happen irrespective of tight glucose control. Interestingly, participants continued to feel guilt and shame over periods of less-than-ideal glycemic control. Thus, a self-defeating logic emerged: participants showed a tendency to overemphasize the impact of poor glycemic

control and underemphasize the impact of tight glycemic control. As a researcher who has lived with T1 diabetes for eighteen years, I wish to add that I too ascribe to this logic and share the participants' anxieties. This logic further contributes to internalizing the belief that one is a "bad diabetic" and must strive for complete control. Such understandings create a demand for additional emotional labour on two fronts: first, the act of striving for perfect control is itself a form of emotional labour as it requires the participant to allocate vast amounts of emotional resources to towards glucose management (thus, one must build one's entire life around managing diabetes). And second, when feelings of failure, guilt, and shame inevitably arise when absolute control is revealed to be impossible, the individual must further expend emotional labour on processing and managing those negative emotions and beliefs.

I would like to try my hand at identifying from where these logics and behaviours might arise. After listening to the accounts of nine thoughtful, self-reflexive, and passionate young women, it is my observation that these corrosive feelings of being a "bad diabetic" and feeling the need to maintain perfect glycemic control may derive from a singular message that every child and some adults with diabetes receive upon diagnosis, and it always goes something like this: "You can be just like everyone else. You can do whatever you want. Diabetes doesn't define you."

Understandably, healthcare providers feel an obligation to give their juvenile (and sometimes adult) patients hope that they can tolerate the challenges ahead, and that with careful management, they can live a life as close to normalcy as possible. It is also understandable that parents and newly diagnosed patients cling to this hope; maybe, their lives don't have to irrevocably change after all. There is an optimism that if one works hard, takes responsibility for their health, and does their best to *control* their illness—to manage it—they will live a long and fruitful life marked by thriving and all the same joys that another

without diabetes would. However, as my participants indicated, this is far from a given truth, and even in ideal circumstances where glycemic control is excellent and complications remain absent, the sheer emotional weight of unending management is irreconcilable with any semblance of able-bodied normalcy.

We have seen this logic at play out regularly in the global COVID-19 pandemic. In the first year of the pandemic, people (COVID deniers and anti-vaxxers notwithstanding) flocked together under the banner of collective and individual responsibility. They believed that their efforts would—no, *must*—yield results. And yet when there was no tangible reward; when the pandemic never receded and there was no normalcy to return to, optimism crumbled to apathy and resignation (Renault, 2022). As someone with diabetes, I watched my society collectively experience what I had for years: the cruelty of an optimism that can never yield the fruits of the labour it instigated. Yet public health measures work not because there is a tangible reward, but because they help us mitigate the risk of a worst-case scenario. Likewise, diabetes management does not guarantee a “normal” life; it merely mitigates *one* of the risk factors for complications.

No one with diabetes sets out on this journey with the intention of fixating on notions of control and internalizing their HbA_{1c}s as a marker of their self-worth. Just like our society on the eve of the COVID-19 pandemic, newly diagnosed patients, under the guidance of their doctors and educators, learn optimism to cope with their illness because there is an unspoken assumption that the goal is to achieve a standard of health and wellness that is as close to that of the able-bodied individual as possible. Striving for longevity and minimizing the presence of diabetes in one’s life dominate how we conceive of and structure care and diabetes education, and to endeavour for those two goals, optimism is required.

However, optimism in itself is not inherently positive. In her book *Cruel Optimism* (2011), Lauren Berlant writes, “Optimism might not *feel* optimistic. Because optimism is

ambitious, at any moment it might feel like anything, including nothing: dread, anxiety, hunger, curiosity, the whole gamut...” (Berlant, 2011, p. 2). They go on to clarify that:

Optimism is cruel when the object/scene that ignites a sense of possibility actually makes it impossible to attain the expansive transformation for which a person risks striving; and, doubly, it is cruel insofar as the very pleasures of being inside a relation have become sustaining regardless of the content of the relation, such that a person [finds themselves] bound to a situation of profound threat that is, at the same time, profoundly confirming (p. 2).

Here, the possibility ignited by optimism is that of a life of able-bodied normalcy. The thing required to attain this possibility is strong glycemic management, and such management is only facilitated through control. As a result, the pleasure of striving for the possibility of able-bodied normalcy is inevitably corrupted by its material and emotional impossibility. Good glycemic control is a tenuous and fragile thing; once it is attained, it is always under threat, and when it is absent, it confirms the impossibility of able-bodied normalcy.

The rhetoric around how things ought to be, or that they can be “fine” and “normal” does not permit people with diabetes to process their own feelings in relationship to their diabetes, and it does not allow them to consider what management and care look like to them. The insistence on a relentless positivity and an emphatic focus on control creates an impossible task which the patient cannot help but fail at some point. When contrasted to all these positive directives, the patient is no longer a human struggling with diabetes; they are a “bad diabetic” failing to work hard enough for the possibility with which they have vested their optimism. This is not to say that positive reinforcement has no place, but it perhaps needs greater tempering, and there ought to be more allowance for patients to experience a full range of emotional responses to their illness.

Although unconventional for a discussion chapter, I would like to touch on a piece of an interview with one of my participants that I think highlights the point. P5, who has no memory of life without diabetes, was constantly told that she was like everyone else and could do whatever she wanted—the standard narrative for a juvenile patient. She said to me:

The main root of why I wasn't taking care of myself is because managing T1 is a full-time job, which, in my mind, is kind of like self-care; you only take care of it if you think you're worth taking care of, and it's a lot of stuff to do. I did not have any ounce of self-esteem or self-love, so I couldn't put the work into it, because I didn't think I was worth that amount of effort. When I actually wrote it down, I started seeing the whole story because I don't remember not having diabetes; it was always like this for my whole life. So, actually seeing it on paper and seeing all of my struggles—not just living it day to day, but seeing the whole overview—you're like, 'Holy sh*t, that's a lot of crap for a person to go through.' I think that kind of gave me a newfound respect for myself.

Writing her story down helped P5 externalize her feelings and distance herself from her lifelong experience of living with T1 diabetes. In this externalization, she was able to gain insight into how resilient she is and how much hardship she has endured, which in turn became a source of self-worth and positive self-regard.

Another pivotal moment for P5 was the sheer physical pain that resulted from medical complications related to poor glycemic control. Her pump site continuously became infected due to elevated blood glucose, and the infections were so painful that she had to be carried to the ER and begged the surgeon to cut off her leg (where the pump site was). During the worst of these episodes, P5's desire to live overpowered what she identified as poor self-esteem. She thought, "Shouldn't I at least give it a go?" and darkly elaborated, "If all goes to sh*t, then [diabetes] will probably take me out in the end anyways." This quote highlights her

sense of futility, but it also suggests the importance that futility plays in the recovery process. I have touched on futility as an emotion that arises when optimism begets the painful realization that the possibilities to which one is attached can never be actualized. However, I want to suggest that just as optimism is not inherently positive, futility, its perceived opposite, is not inherently negative. Rather, it can pave the way for a more enduring kind of empowerment than a fickle optimism. For P5, finding herself at an absolute emotional low provided her the space to recognize an avenue towards a better life.

Moments of futility create a contrast between *what is* and *what is expected*, and this reveals the degree to which the pretense or veneer of management and control elicits a performance of self-care even when one feels unworthy of care. Futility, then, is not merely an excessive focus on the negative but brings to light a perspective on how one's life could be different. Futility presents an honest recognition of hardship, which can in turn provide emotional liberation from the constraints of external expectation. Emotional labour involves managing a pretense for the comfort of others, and futility, which arises from an emotional "rock-bottom," creates a space in which one no longer feels compelled to mitigate and manage for the sake of others. Ultimately, it required something external to P5's will to motivate change, which also highlights that the care she was receiving up until that point was not helping her. Unfortunately, it may have worked against her by holding an expectation that P5 was unable or unwilling to meet.

In his book, *The Already Dead* (2012), Eric Cazdyn plucks a line from Sigmund Freud's letter to Marie Bonaparte, which was written only two years before his death. At the time, Cazdyn explains, Freud was in a great deal of pain—both physically and psychologically—due to oral cancer and the Nazi advance into Austria. Freud wrote: "In order to find all of this bearable, one must remind oneself constantly that one really has no right to be living any longer" (from Cazdyn, 2012, p. 5). Cazdyn then challenges us to

consider an inversion of Freud's statement: "In order to find the current moment unbearable, we must remind ourselves that we really have the right to die" (p. 5). The point here is that in a culture committed to health and longevity, our impulse is to frame the unbearable as bearable. P5's situation demonstrates how difficult it can be to acknowledge that what we have been conditioned to regard as bearable, is, in fact, potentially unbearable. This recognition, however, is powerful in that it can subvert the expectations placed on the chronically ill to manage endlessly in the name of longevity and able-bodied normalcy. P5 is an excellent example of the detriment that this demand can produce. In the constant narrative that one with diabetes must manage their illness under the pretense of mimicking social and physical normativity, the degree of immeasurable strength and resilience displayed by the person with diabetes is rendered invisible. The frenzied bid to decree them normal and their condition bearable is perhaps not a kindness, but an added expectation of emotional, physical, and psychological labour. It is, in Berlant's conceptualization, a kind of cruel optimism. Perhaps, then, it would be more charitable, more compassionate, to acknowledge that there is something unbearable in the demand for constant (unachievable) control, and that the resolve to live with the unbearable makes those with T1 diabetes truly remarkable.

Limitations

Methodological limitations included the researcher's personal relationship to T1 diabetes and her own lived experiences, which informed the assumptions on which the study is built. These assumptions included the belief that T1 diabetes is an emotionally and psychologically taxing illness for a significant number of people who live with it. Furthermore, the researcher's epistemological and ontological assumptions necessarily impact the way in which the research formulates questions and approaches interviews. The researcher's positionality was considered throughout the process, and self-reflexivity was exercised through the use of journaling to minimize unconscious insertion of personal

opinions and judgments. Rather than striving for the complete elimination of bias, the researcher strove to be aware of the way in which her bias impacts the research and the narrative it produces about living with diabetes.

The research covered difficult and emotionally sensitive topics. While consent forms explaining the risk of psychological and emotional distress were provided and signed by each participant, the researcher strove to minimize an impression of authority that may impact participants negative or make them feel pressured to answer questions they are uncomfortable with. The researchers strove at all times to be aware of the power dynamic between researcher and participant and strove to create a comfortable and easy-going atmosphere during interviews while reminding participants that they were free to excuse themselves from the interview or forego answering questions at any time.

Importantly, all efforts were made to preserve anonymity and privacy given the online nature of the interviews. The application's safety features were evaluated and used to their full extent, and participants were informed when the recording began and ended. All files are stored on AU's Office 365, which is password protected, and participants were assigned numerical aliases during the transcription and write-up to protect their identity.

The results of the research are limited by the somewhat homogenous demographics of the participants. First, all participants identify as women, which limits the broader applicability of the results. Second, 78% of participants were European White, thus, the perspectives and experiences of racialized and ethnic minorities were not as prominent in the study as the researcher would have desired. Third, although education status was not probed during the interview, eight of the nine participants voluntarily disclosed that they had graduated from a post-secondary institution, with two participants disclosing that they were enrolled in or had completed a graduate program. Thus, the overwhelming majority of participants share a similar level of education, which affords them a greater breadth of critical

language to engage the subject matter. Thus, this group of participants' particular engagement with the concepts and subject matter may not be reflected in the broader population. Due to the sample's size and relative homogeneity, the study participants therefore are not representative of the broader population of people living with diabetes. Lastly, cultural differences between regions were not heavily considered in the study. While Canada and the United States share much, there are also significant differences in how their healthcare systems and societies operate both on a local and regional level.

Recommendations

Qualitative research on the experience of living with diabetes is neglected in a scholarly landscape that privileges quantitative study. While existing literature has established that living with diabetes is difficult, my research has demonstrated a need to explore in more detail and with greater nuance why it is difficult. Ideally, this study should be replicated with a more diverse population and with a much larger sample size. Attention to demographic factors such as race/ethnicity, socio-economic status, education level, and local institutions is paramount, as these factors may inform participant perspectives and offer insight into the unique challenges of different populations.

Furthermore, a re-evaluation of current praxis in both educational and medical settings is warranted. Specifically, the role of deeply ingrained ableism in how healthcare providers and educators imagine their patients *should* be living ought to be reckoned with, and models for provider and patient education ought to be reconsidered. I would especially encourage a reconsideration of the role of optimism in patient counseling and education and the assumptions upon which it is built, the promise of possibility it ignites, and the long-term impact it may have patients' expectations of themselves.

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Appendix A: Diabetes Distress Scale**DDS**

DIRECTIONS: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
4. Feeling angry, scared and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
6. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
7. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
8. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

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	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
9. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6
10. Feeling that diabetes controls my life.	1	2	3	4	5	6
11. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

Appendix B: Diabetes Distress Scale Scoring Sheet

DDS1.1 SCORING SHEET

INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress.¹ To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale.

Current research² suggests that a mean item score 2.0 – 2.9 should be considered 'moderate distress,' and a mean item score ≥ 3.0 should be considered 'high distress.' Current research also indicates that associations between DDS scores and behavioral management and biological variables (e.g., A_{1c}) occur with DDS scores of ≥ 2.0 . Clinicians may consider moderate or high distress worthy of clinical attention, depending on the clinical context.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores.

It may be helpful to inquire further or to begin a conversation about any single item scored ≥ 3 .

Total DDS Score: a. Sum of 17 item scores. _____
 b. Divide by: _____17_____
 c. Mean item score: _____
 Moderate distress or greater? (mean item score > 2) yes___ no___

A. Emotional Burden: a. Sum of 5 items (1, 4, 7, 10, 14) _____
 b. Divide by: _____5_____
 c. Mean item score: _____
 Moderate distress or greater? (mean item score > 2) yes___ no___

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B. Physician Distress: a. Sum of 4 items (2, 5, 11, 15) _____

 b. Divide by: _____4_____

 c. Mean item score: _____

 Moderate distress or greater? (mean item score > 2) yes___ no___

C. Regimen Distress: a. Sum of 5 items (6, 8, 3, 12, 16) _____

 b. Divide by: _____5_____

 c. Mean item score: _____

 Moderate distress or greater? (mean item score > 2) yes___ no___

D. Interpersonal Distress: a. Sum of 3 items (9, 13, 17) _____

 b. Divide by: _____3_____

 c. Mean item score: _____

 Moderate distress or greater? (mean item score \geq 2) yes___ no___

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Appendix C: Consent Form, Recruitment Poster, and Invitation to Participate

LETTER OF INFORMATION / INFORMED CONSENT FORM

T1 Diabetes and Emotional Labour in Young Adults

[Insert date]

Principal Investigator (Researcher):

Alexandra Jovic
Master of Health Studies
Ajovic1@athabasca.edu

Supervisors:

Karen Cook PhD RN
kcook@athabasca.ca
Gwen Rempel PhD RN
grempel@athabasca.ca

You are invited to take part in a research project entitled ***T1 Diabetes and Emotional Labour in Young Adults***.

This letter is part of the process of informed consent. The information presented will give you the basic idea of what this research is about and what your participation will involve, should you choose to participate. It also describes your right to withdraw from the project. To decide whether you wish to participate in this research project, you need to understand about the risks, benefits and requirements; then you can make an informed decision. This is the informed consent process. Take time to read this carefully. Please contact the principal investigator, Alexandra Jovic, if you have any questions about the project or would like more information before you consent to participate.

It is entirely up to you whether or not you take part in this research. If you choose not to take part, or if you decide to withdraw from the research once it has started, there will be no negative consequences for you now, or in the future.

Introduction

My name is Alexandra Jovic and I am a Master of Health Studies student at Athabasca University. As a requirement to complete my degree, I am conducting a research project about the experience of living with type 1 (T1) diabetes. Specifically, I am investigating whether young adults living with T1 diabetes expend emotional labour in the management of their condition. I am conducting this project with the supervision of Dr. Karen Cook and Dr Gwen Rempel.

Why are you being asked to take part in this research project?

You are being invited to participate in this project because you are between the ages of 18 and 30 and have lived with T1 diabetes for at least two years.

What is the purpose of this research project?

The purpose of this research is to deepen understandings of what it is like to live with T1 diabetes as a young adult. We know that people with diabetes are more likely to experience distress related to their illness but we do not yet understand how and why. This research explores whether young adults with T1 diabetes expend emotional labour as part of managing and coping with their illness. Furthermore, I want to understand if the idea of emotional labour is relevant to those living with T1 diabetes.

What will you be asked to do?

Your participation involves a semi-structured interview with the principal researcher that will be scheduled at your convenience. The interview will be conducted over Zoom and will last 1-2 hours. During the interview, I will ask you about your experiences with T1 diabetes, and the conversation will follow points of interest you raise. The interview may include personal questions about how T1 diabetes impacts you, your interpersonal relationships, and your

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social dynamics more broadly. The interview will be recorded and transcribed for data analysis.

Although a follow-up conversation is not necessary, I am available to review your interview transcript with you and make changes to your answers if at any point you wish to do so. I will also be available via email or for a scheduled call to answer any questions or concerns regarding the interview.

What are the risks and benefits?

Discussing sensitive topics such as your experiences living with T1 diabetes may cause emotional or psychological distress. If at any point during the interview you feel that you cannot continue, you are welcome to stop the interview. You can tell me whether or not you want to continue the interview at a future time. You can also tell me that you want to withdraw your participation from the study. Please know that you are under no obligation to complete the interview. Participation in research is **always** voluntary, through every stage of the research process. With your permission, I will also do a follow-up email within 48 hours of the interview to check in with you.

There are also benefits to participating in this research. As someone living with T1 diabetes, you will be given the opportunity make your voice heard by the health care community. You may learn more about your relationship to T1 diabetes, find new ways to talk about living with diabetes, and you may find the research conversation to be cathartic. Finally, you will play a vital role in expanding health researchers' understanding of how and why living with T1 diabetes can be challenging. This understanding is important for developing knowledge and working towards better policies, practices, and training for healthcare professionals.

Do you have to take part in this project?

As already stated, involvement in this project is entirely voluntary. If at any point you wish to withdraw your participation, please inform me, Dr. Cook, or Dr. Rempel. You are welcome to email me at any time prior to the interview to withdraw your participation. Furthermore, if you wish to stop the interview partway through, please do not hesitate to tell me. I will ask you whether you would like the data collected up until that point to be discarded or used in the study. If you would like me to remove the data, I will stop recording, and your data will be permanently deleted immediately following the interview.

How will your privacy and confidentiality be protected?

The ethical duty of confidentiality includes safeguarding participants' identities, personal information, and data from unauthorized access, use or disclosure.

During the interview, the video call application's safety features will be used in full to ensure that risks are mitigated, and to ensure that your privacy is protected. The call will require a password that is only accessible to you and the researcher, and each participant will receive a separate link and password for their call. Audio recordings of the interview and transcripts will be stored on a password protected online storage application – Microsoft Office 365. The application will have two-step verification activated for an added layer of security.

In the research write-up and documentation (such as file naming), participants who wish to remain anonymous will provide or be given aliases to protect their identity, and all audio recordings will be permanently deleted after the research project is completed and accepted by my committee. Interview transcripts will be archived on a password protected storage application with two-step verification unless otherwise specified by the participant. All information will be held confidential, except when legislation or a professional code of conduct requires that it be reported.

To learn more about Zoom's privacy policies, visit: <https://zoom.us/privacy>

How will my anonymity be protected?

Anonymity refers to protecting participants' identifying characteristics, such as name, home town, care centre, or description of physical appearance.

You will be asked at the beginning of the interview if you wish to remain anonymous. All participants who wish to be anonymous will provide or be given aliases throughout the research process so that their names cannot be identified. Furthermore, participants are welcome to turn off their cameras during the interview. Participants will be asked to broadly identify their region of residence (i.e., a province or state) for demographic purposes, but this should not pose any substantive risk to anonymity. Since data is stored on a password protected application with two-step verification, the possibility of identifying a participant's voice is low, as only the Principal Investigator (Jocic) and Supervisors (Cook and Rempel) will have access to these audio files.

Every reasonable effort will be made to ensure your anonymity; you will not be identified in publications or presentations without your explicit permission. If you do not wish to remain anonymous, this is an option that will be available to you.

How will the data collected be stored?

Audio recordings of the interview and transcripts will be stored on a password protected in Athabasca University's Office 365. The application will have two-step verification activated for an added layer of security. Only the researcher will have access to the audio recordings, though interview transcripts may be made available to the researcher's supervisors at Athabasca University.

Audio files will be stored on Athabasca University's Office 365. Interview transcriptions will be archived on Office 365 as well, with two-step verification unless otherwise specified by the participant.

I may seek to use these transcripts in future work that further explores living with T1 diabetes and will require REB approval if a later project is designed.

Who will receive the results of the research project?

The research results will be disseminated to my supervisory committee and any external reviewers as part of the completion of my degree. Furthermore, I may seek to have the results published in a scholarly journal. With the participant's consent, the write-up of the final project may use direct quotations from the interview to illustrate themes that emerge from the data but no identifying information.

The existence of the research will be listed in an abstract posted online at the Athabasca University Library's Digital Thesis and Project Room and the final research paper will be publicly available.

Who can you contact for more information or to indicate your interest in participating in the research project?

Thank you for considering this invitation. If you have any questions or would like more information, please contact me, (the principal investigator) by e-mail ajocic1@athabasca.edu or my supervisors by email at kcook@athabasca.ca and grempel@athabasca.ca.

If you are ready to participate in this project, please complete and sign the attached Consent Form and return it by email to ajocic@athabasca.edu.

Thank you.

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Alexandra Jovic

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718.

Informed Consent:

Your signature on this form means that:

- You have read the information about the research project.
- You have been able to ask questions about this project.
- You are satisfied with the answers to any questions you may have had.
- You understand what the research project is about and what you will be asked to do.
- You understand that you are free to withdraw your participation in the research project without having to give a reason, and that doing so will not affect you now, or in the future.
- You understand that if you choose to end your participation **during** data collection, any data collected from you up to that point will be retained by the researcher, unless you indicate otherwise.
- You understand that if you choose to withdraw **after** data collection has ended, your data can be removed from the project at your request up until data analysis begins.

	YES	NO
I agree to be audio-recorded	<input type="radio"/>	<input type="radio"/>
I agree to be video-recorded	<input type="radio"/>	<input type="radio"/>
I agree to the use of direct quotations	<input type="radio"/>	<input type="radio"/>
I allow my name to be identified in any publications resulting from this project	<input type="radio"/>	<input type="radio"/>
I allow anonymized transcripts of my interview to be securely archived on Athabasca University's Office 365.	<input type="radio"/>	<input type="radio"/>
I allow anonymized audio recordings of the interview to be securely archived on Athabasca University's Office 365.	<input type="radio"/>	<input type="radio"/>
I am willing to be contacted following the interview to verify that my comments are accurately reflected in the transcript.	<input type="radio"/>	<input type="radio"/>
I agree to a follow-up communication to check on my well-being following the interview.	<input type="radio"/>	<input type="radio"/>
I understand that the interview data I provide for this study may be analyzed in future studies.	<input type="radio"/>	<input type="radio"/>

Your signature confirms:

- You have read what this research project is about and understood the risks and benefits. You have had time to think about participating in the project and had the opportunity to ask questions and have those questions answered to your satisfaction.
- You understand that participating in the project is entirely voluntary and that you may end your participation at any time without any penalty or negative consequences.
- You have been given a copy of this Informed Consent form for your records; and
- You agree to participate in this research project.

Signature of Participant

Date

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Principal Investigator's Signature:

I have explained this project to the best of my ability. I invited questions and responded to any that were asked. I believe that the participant fully understands what is involved in participating in the research project, any potential risks and that he or she has freely chosen to participate.

Signature of Principal Investigator

Date

PARTICIPANTS NEEDED FOR
RESEARCH IN T1 DIABETES

We are looking for volunteers to take part in a study about living with T1 diabetes.

As a participant in this study, you would be asked to participate in a one-on-one interview with the researcher.

Your participation is **entirely voluntary** and would take up approximately 1-2 hours of your time. By participating in this study, you will help us to have your voice heard by the health care community and play a role in expanding our understanding of what it's like to live with T1 diabetes so that we can develop better policies and practices for diabetes care.

To learn more about this study, or to participate in this study,
please contact:

Principal Investigator:

Alexandra Jovic, Master of Health Studies student, Athabasca University

Contact:

Please email me at ajocic1@athabasca.edu or send me a direct message on social media.

This study is supervised by: Dr. Karen Cook & Dr. Gwen Rempel

This study has been reviewed by the Athabasca University Research Ethics Board.

LETTER OF INFORMATION / INFORMED CONSENT FORM

T1 Diabetes and Emotional Labour in Young Adults

March 26, 2021

Principal Investigator (Researcher):

Alexandra Jovic
Master of Health Studies
Ajovic1@athabasca.edu

Supervisors:

Karen Cook PhD RN
kcook@athabasca.ca
Gwen Rempel PhD RN
grempel@athabasca.ca

Dear Potential Participant,

This email is to invite you to participate in a qualitative research project about the experience of living with type (T1) diabetes.

The purpose of this research is to deepen understandings of what it is like to live with T1 diabetes as a young adult. This research explores whether young adults with T1 diabetes expend emotional labour as part of managing and coping with their illness. Furthermore, I want to understand if the idea of emotional labour is relevant to those living with T1 diabetes. I too live with T1 diabetes and am conducting this project as part of my graduate studies under the supervision of Dr. Karen Cook and Dr Gwen Rempel.

I invite you to participate in this project because you are between the ages of 18 and 30 and have lived with T1 diabetes for at least two years. Your participation involves a semi-structured interview with the principal researcher that will be scheduled at your convenience. The interview will be conducted over Zoom and will last 1-2 hours. During the interview, I will ask you about your experiences with T1 diabetes, and the conversation will follow points of interest you raise. You can be expected to talk about emotional labour, which includes things like managing complex emotions that arise as a result of diabetes management. The interview may include personal questions about how T1 diabetes impacts you, your interpersonal relationships, and your social dynamics more broadly. The interview will be recorded and transcribed for data analysis.

Although a follow-up conversation is not necessary, I am available to review your interview transcript with you and make changes to your answers if at any point you wish to do so. I will also be available via email or for a scheduled call to answer any questions or concerns regarding the interview. Furthermore, you will be compensated for your time with a \$25 Amazon gift card, sent directly to your email address.

As someone living with T1 diabetes, you will be given the opportunity to make your voice heard by the health care community. You may learn more about your relationship to T1 diabetes, find new ways to talk about living with diabetes, and you may find the research conversation to be cathartic. Finally, you will play a vital role in expanding health researchers' understanding of how and why living with T1 diabetes can be challenging. This understanding is important for developing knowledge and working towards better policies, practices, and training for healthcare professionals.

Please see the attached Information Letter for further details, and if you would like to participate, please complete the Informed Consent Form. You may also complete the consent form online using the following link:

<https://forms.office.com/Pages/ResponsePage.aspx?id=JsKqeAMvTUuQN7RtVsVSECIgy7M9RqFOupGI70dR7ipUN1IBRTVSVkYwR1IxMDBaSINGVjIMNzIFVy4u>

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Your participation would be greatly appreciated and will be valuable in understanding and enhancing the experience of nurses working and studying during COVID-19. Should you decide to participate, please refer to and sign the Informed Consent Form.

Thank you for considering this invitation. If you have any questions or would like more information, please contact me, (the principal investigator) by e-mail at **ajocic1@athabasca.edu**.

Sincerely yours,

Alexandra Jocic

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718.

Appendix D: Reflexive Journaling Samples

Journal Entry 1: Analyzing My Beginnings

In the first week of this course, I've been thinking a lot about why I want to research T1 diabetes in young adults and psycho-social issues. I've also been reflecting on my emphasis on emotional labour, and why I think it's such a useful idea. Why qualitative research? Why the intimate emphasis on inner processes and experiences? I'd barely gotten through a page of one of the readings when a particular line struck me: "You can't analyze others until you've analyzed yourself" (Saldana, 2019, p. 2036). I would agree with this, and I think it scrapes at why diabetes in young adulthood and emotional labour are such important topics for me *now*, at this particular juncture in my life.

One question I've been asked a lot is why I didn't pursue diabetes research sooner; I started on the right track with a BA in Psychology, but why did I go on to do an MA in comparative literature? Why a PhD on the supernatural and its relationship to historical violence? Why wait nearly a decade after the rawness of my life's most difficult years had passed?

The answer to me was always simple: I wasn't ready. How could I turn my gaze on others when I had yet to turn it on myself? My early 20s were spent in a haze of confusion, self-loathing, shame, and guilt. Bouncing between indifferent and judgmental physicians; listening to my endocrinologist's residents lecture me on the dangers of high blood sugar; soothing my simultaneously anxious and angry family members. It was a very bad time indeed. My only respite came in the form of therapy once a week—a special program for chronically ill people at Women's College Hospital. My psychiatrist was a young immigrant woman I shared a lot in common with. I could tell, intuitively, that many of my struggles with my overprotective immigrant parents were familiar to her, that the unreasonably high expectations that had been placed on me weren't something I could simply walk away from

with a defiant, “F*ck you, mom!” This taught me the importance of a compassionate physician who had enough reflexivity to parse when a standard suggestion like, “Have your thought of moving out?” wouldn’t be helpful.

I was happy when she allowed me to skip right over the diabetes, right over the rote questions about how I felt about being ill. She let me vent about whatever I wanted. Rather than setting the pace and discussion topic, she allowed me agency and control when I felt I had none elsewhere. It turned out that working through my interpersonal and familial baggage was far more productive in helping me do better with my diabetes. After all, how could I manage an illness that required constant awareness when I was so busy keeping everyone but myself reassured that it was going to be okay, even when I wasn’t sure that it was?

I was in therapy for a year. I would have continued, but my psychiatrist was moving provinces. She offered a referral to someone new, but for reasons I can’t remember, I declined. At that point, I was recovering. At that point, telling myself, “Why not just try?” didn’t seem so daunting. The stars aligned—a miraculous synchronization of intent, action, and circumstance—and the universe gifted me the opportunity to do better.

First, my work in therapy had given me *insight*. Second, I got a dog. That sounds weird—maybe like it shouldn’t matter—but to this day I’m convinced some unconscious part of my brain knew it would help. See, in an isolated family of three, triangulation is impossible to escape. It’s always two against one, and more often than not, I was the ‘one’. I was an easy outlet, a problem my parents could unite over, a fragile suture over a deep, festering wound. But a dog became the fourth family member, and that disrupted *everything*. There was something for them to focus on that wasn’t me. Lastly, I went to Japan for six months at the behest of my MA supervisor. I was studying Japanese literature, after all. It turned out to be not-the-greatest experience, but it gave me something I desperately needed:

distance. My parents were forced to learn how to live without me, and I was permitted to feel just a little bit less accountable for their feelings. I didn't *have* to be responsible for their happiness anymore, so I could finally be responsible for mine.

Academia became my way of talking about personal demons without actually talking about personal demons. I study the supernatural and its relationship to violence. It sounds abstract, and looking back, it was an abstraction of my own experience. Chronic illness is if nothing a kind of violence, and living with something you can't see or feel that could also kill you if you don't pay attention to it is if nothing a little bit supernatural. When you have a chronic illness, reality shifts. Your relationship to time isn't the same anymore because in a manner of speaking, you're already dead; you're waiting for the inevitable, maintaining a stasis until it no longer becomes possible. Every finger prick is a reminder of your mortality. Doctors tell you the insulin pumps and CGMs make it easier, but what they don't tell you is how they also make it worse. They're a permanent reminder not just of the illness, but of your agency in how you manage it. The outcome is on *you*.

Other people don't understand the inordinate amount of responsibility expected of someone with diabetes. Even worse, however, is that people with diabetes aren't aware of the inordinate amount of responsibility they've internalized. For me, therapy was just the beginning. I never once considered researching diabetes because it was the demon I faced off with every day, the old hag on my back cackling at me for every stumble and misstep, until one day, I stopped feeling the weight. I only realized it was there when it lifted ever so slightly, when for the first time, I wrote about my direct experience with diabetes in a graduate seminar on haunting, and my anthropology professor asked me, "Have you thought about doing work on this?"

The hag lost her balance, and I thought, "Why the hell not?"

So when people ask me why I didn't get into diabetes research sooner—especially in a qualitative capacity—the answer is simple: I wasn't ready. The excavation site runs deep, and as far as I'm concerned, there is no sense in digging around other people's souls until you've dug around your own. I've done a lot of digging, and this has given me confidence that I can help other people dig too. It's also taught me that other people won't be honest with you unless you're honest with yourself. That degree of self-reflexivity doesn't come overnight. I think for this particular research topic—one that demands its subjects be vulnerable—the researcher will also have to be vulnerable. And for that, I am finally (probably) ready.

To end I want to circle back to Saldana, whose words struck a deep, emotional cord in me, and encapsulate so much of why I am drawn to qualitative research:

...being a qualitative researcher means **knowing and understanding yourself**—knowing and understanding yourself so deeply that it scares the hell out of you. You are your own case study, a mirrored perception of self that is reflective, reflexive, and refractive about your age, your gender, your ethnicity, your sexual orientation, and all the myriad of ways you categorize and construct your personal identities. It's dwelling deeply in your own presence, knowing where you are in place and positionality, in space and standpoint, in context and in contrast. It's knowing that if you think and feel a certain way, then perhaps others do too. And maybe that means a connection, a relationship, possibly a universal truth.

You can't analyze others until you've analyzed yourself (Saldana, 2019, p. 2044).

Journal Entry 2: Reflexivity and a lens on gender.

One of my interests regarding psychosocial issues in young adults with T1 diabetes is deeply influenced by my experience of gender, and the ways in which medical knowledge is often gendered. One of the most common psychosocial issues seen in young women with diabetes is *diabulimia* and various degrees of disordered eating.

Many young adults struggle with blood glucose control in their teens and twenties. However, what grated me most as a young woman with poorly controlled diabetes was the assumption that my sudden poor control must have been the result of a very gendered notion of poor self-esteem and a desire to lose weight. Rather than having clinicians try to understand the complex tapestry of interconnected issues that impacted me, my poor glucose control was reduced to the basest understanding of my gender. What I found in medical discourse and through personal reflection was that everything consisted of half-truths: yes, *diabulimia* is a real issue that in medical literature primarily affects young women. Yes, I struggled to maintain a body weight I was happy with because of the immense weight gain that resulted from insulin therapy. Yet neither of those things in isolation accurately describe my experience or explain why I had poor blood glucose control. For one, my discomfort with my weight felt excessively pathologized. And second, the sloppy causal relationships assumed by my physicians wound up doing far more harm than good. In the end, I felt alienated from my own experience and struggled for years to articulate that despite struggling with my weight and blood sugar management, I did not have an eating disorder; having the symptoms of an illness did not necessarily mean I had that illness.

It was only years later when I voluntarily worked with a psychiatrist on my family dynamics that my blood glucose began to improve. What shocked me most was that my therapist and I spent very little time discussing diabetes; the vast majority of our sessions revolved around my personal life.

These experiences have made me highly critical of medical science's claims to objective fact. Women with poor blood glucose control are suspected of having eating disorders, but men who display the same behaviour are understood as simply behaving recklessly. These are, in my view, gendered readings of the same behaviour. However, as someone who has been raised in such a society, in such an institution, I cannot absolve myself of falling into the same traps. What are gendered assumptions I hold about myself and others? How will I approach gender non-conforming individuals? Perhaps most concerning to me is the question of how I will respond when I meet someone who does, in fact, align with hegemonic expectations? Will I resist accepting this because of my desire to subvert commonly accepted narratives?

Being well-versed in critical theory, I worry that in speaking with participants in future studies, I will want to critique the way some of them might explain their experiences. For example, what will I do if I do not believe what a participant tells me, or if I find their explanations superficial or lacking in useful details? I am well aware that as a researcher, I have a specific goal, and my own experience of gender impacts that the way I will want to approach gendered discourse in diabetes care. I must always strive, then, is to practice self-reflexivity and interrogate my reactions, especially reactions of discomfort or frustration that may arise when my expectations are not met in the research process.

Journal Entry 3: How do I Want to Approach this Research and Why?

This week, I've been thinking a lot about phenomenology, as its this has been the qualitative research method I've been most drawn to for my topic. For my research, I want to explore whether the concept of emotional labour might be viable in shedding light on why living with T1 diabetes leads to diabetes distress and other mental health challenges. In order to do this, it is undoubtedly important to understand how the psychological and emotional burden of diabetes management is experienced by people living with the condition. To get a better handle on phenomenology, I turned to Neubauer et al. (2019)'s article on transcendental and hermeneutic phenomenology. Although there are other types as well, I enjoyed the focused analysis of these two specific theories of phenomenological research.

What struck me immediately was the assertion by the researchers that phenomenology does not have a strong following, and that a major barrier to its use is lack of methodology (Neubauer et al., 2019, p. 91). However, phenomenological research is very important; it is essential in helping scholars learn from the experiences of others, and broadly speaking, the very notion of closely examining a subject is a foundational premise of research (an individual, group, society, or object). Neubauer et al. (2019) argue that, "The questions that phenomenology can answer, and the insights this kind of research can provide, are of foundational importance to health professions education (HPE) scholars" (Neubauer et al., 2019, p. 91). For example, what does it mean to be an empathetic clinician?

Phenomenology is defined by Neubauer et al. (2019) as a discipline that "seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it. The goal of phenomenology is to describe the meaning of this experience—both in terms of *what* was experienced and *how* it was experienced" (Neubauer et al., 2019, p. 91). They go on to argue that, "By examining an experience as it is subjectively lived, new meanings and appreciations can be developed to inform, or even re-orient, how we

understand that experience” (Neubauer et al., 2019, p. 92). The article calls on researchers to consider the various philosophies underpinning phenomenological research, and to decide which philosophy they embrace in order to choose the right methodology. Reading this article, I decided to do this myself using the information Neubauer et al. (2019) presented for transcendental phenomenology and hermeneutic phenomenology. For ease, I have taken a screen shot of their handy chart and pasted it here, and marked which of the philosophical, ontological, epistemological, and methodological assumptions I ascribed to in order to see if I could identify as either a transcendental phenomenologist or a hermeneutic phenomenologist.

***Chart is below

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B. E. Neubauer et al.

Table 2 Comparison of transcendental and hermeneutic phenomenology

	Transcendental (descriptive) phenomenology	Hermeneutic (interpretive) phenomenology
Philosophical origins	Husserl ✓	Heidegger Gadamer ✓
Ontological assumptions	Reality is internal to the knower; what appears in their consciousness	Lived experience is an interpretive process situated in an individual's lifeworld
Epistemological assumptions	Observer must separate him/herself from the world including his/her own physical being to reach the state of the transcendental I; bias-free; understands phenomena by descriptive means ✗	Observer is part of the world and not bias free; understands phenomenon by interpretive means ✓
Researcher role in data collection	Bracket researcher subjectivity during data collection and analysis ✗	Reflects on essential themes of participant experience with the phenomenon while simultaneously reflection on own experience ✓
Researcher role in data analysis/writing	Consider phenomena from different perspectives, identify units of meaning and cluster into themes to form textural description (the what of the phenomenon). Use imaginative variation to create structural (the how) description. Combine these descriptions to form the essence of the phenomenon ??	Iterative cycles of capturing and writing reflections towards a robust and nuanced analysis; consider how the data (or parts) contributed to evolving understanding of the phenomena (whole) ✓
Methodological texts	Polkinghorne [28] Moustakas [18] Giorgi [27]	Van Manen [12] me!!
Examples	Takavol [32]	Bynum [2]

I was not particularly surprised to find that I ascribed more to Heidegger and Gadamer's understanding of phenomenology. As an undergraduate student, I studied Western philosophy extensively and developed a strong affinity with existential philosophers. When I went on to work on my graduate degrees, I was primarily educated in critical theory, particularly of the post-modern variety. Thinkers such as Foucault, Judith Butler, Benjamin,

Edward Said and other key figures in critical area studies dominated my education. Husserl's epistemological assumption that one can effectively bracket off their subjectivity and separate themselves from the world (even in a physical capacity) strikes as me as both lofty and rooted in European Enlightenment notions of the rational subject—a narrative I have been taught to be critical of.

The words 'bias-free' make alarm bells go off in my head. I simply do not believe that is possible, nor do I believe in any objective, universal truths where experience is concerned. My training has taught me to understand 'truth' as being situated, and to understand experience as relational. Successful bracketing requires the researcher to "set aside the world and the entirety of its content—including the researcher's physical body" (Neubauer et al., 2019, p. 93). The notion that one is even capable of setting aside the tapestry of the 'self' and the threads responsible for weaving that 'self' seems atomizing and arrogant in that they disavow the extent to which reality is tied to context. There is no vacuum into which a researcher can 'bracket' themselves off, where they are not influenced by their positionality. That someone might even suggest such an exercise is perhaps revealing of their own positionality, and how that positionality subsequently impacts their approach in managing researcher bias. However, I fear that such an approach may not adequately promote self-reflexivity; if one is so focused on eliminating bias, they may end up prone to simply denying the ways it permeates their research questions and methodologies. Rather than elimination of bias, I would prefer to opt for transparency and awareness of it.

Furthermore, to bracket one's subjectivity away during data analysis seems somehow counterintuitive to the very purpose of phenomenological research. If the goal is to understand others' experience, I struggle to imagine a productive analysis of that experience without a degree of connection to it. To consider the meaning of an experience without

examining my own relationship to that experience *feels* unnatural, and perhaps even a little bit dishonest.

For these reasons, I have concluded that I am strongly in the hermeneutic camp of phenomenological research. My own understanding of my experience with the phenomenon I wish to study is important to me and serves as a foundational facet of why I want to conduct this research, and how I intend to approach it. I am dedicated to a robust and nuanced analysis of the subject matter, and more than anything, I wish to contribute to a new understanding of how people experience T1 diabetes on an emotional level.

Journal Entry 4

This week, I decided to dig into some IPA studies to get a better sense of how to situate myself in existing research on my topic. I was not able to find any pertinent IPA studies on T1 diabetes and young adults, but I found a study that explored the paternal experience of parenting a young adult with a developmental disability. “‘Shutting the World Out’: An Interpretative Phenomenological Analysis Exploring the Paternal Experience of Parenting a Young Adult with a Developmental Disability” by Thackeray & Eatough (2016) provided me with an excellent framework for how I might want to approach my own research.

In their study, they note that quantitative research on the topic has focused on measures of stress, well-being, adaption, and coping effectiveness of parents with disabled children (Thackeray & Eatough, 2016, p. 179). This echoes my own findings of existing diabetes research on psycho-social challenges; the vast majority is quantitative and focuses on prevalence of stress and specific diagnoses such as depression, anxiety, and eating disorders. Diabetes distress, a recently coined phenomenon, is also measured quantitatively, and the research that brought the diabetes distress scale into use is quantitative. Of all the research I’ve seen, only Jeong et al. (2018) is qualitative and addresses the experience of social stigma for people with T1 diabetes. This has led me to believe that qualitative research on the topic of diabetes and psychosocial issues is grossly underrepresented in the literature.

Returning to Thackeray & Eatough (2016), they note that despite the quantitative study of parents noting higher stress levels, parental experience was qualitatively different across gender. In reading the study’s summary of previous quantitative research, I found myself chuckling at some of the findings: “Parents of disabled children experienced more negative affect, physical symptoms and higher stress levels” (Thackeray & Eatough, 2016, p. 179). Well, no shit. This more or less sums up how I feel about a lot of the quantitative

research around diabetes and psychosocial challenges in young adults. *Of course* people with diabetes will experience more distress, depression, and anxiety than the general population. This seems to be an obvious finding. Yet knowing this has done little to temper the soaring HbA_{1c}s among young adults living with the illness. If anything, I am concerned that this correlation between diabetes and mental health issues has become so ingrained in medical literature that it is simply taken for granted as an unspoken truth, with no one caring to examine the ‘why’ and ‘how’. It becomes self-evident, with little attention being paid to the qualitative experience of the people who live with these challenges.

For example, Thackeray & Eatough (2016) note that qualitative research has shown that parents of children with cerebral palsy both experience grief, yet the way that grief manifests and impacts the marital relationship differs dramatically, with men more prone to avoidance tactics, and women more prone to feeling isolated and unheard (Thackeray & Eatough, 2016, p. 180). In emphasizing the value of IPA, they say that IPA “is interested in garnering a fine-grained contextual perspective on a particular phenomenon as opposed to representing a population...[and] advocates an idiographic approach whereby the participant is positioned as the experiential expert” (Thackeray & Eatough, 2016, p. 181).

Their methods section was particularly illuminating in helping me understand the sort of participants I should be recruiting, the importance of homogeneity in the sample, and possible avenues to take when preparing interviews. For example, interviews are meant to be “participant led so that salient topics introduced by the interviewees could be pursued and further elucidated” (Thackeray & Eatough, 2016, p. 181).

This has given me a great degree of clarity on how I may want to approach my own research. Furthermore, the researchers noted IPA’s commitment to the hermeneutic tradition, which in a previous journal I highlighted as being compatible with my ontology and epistemology about knowledge production. Overall, I feel more confident about pursuing

research with IPA.

Journal Entry 5

As I started making my way through interviews, a common underlying theme I noticed among participants was the question of how one deals with the reality of living with a chronic illness that requires constant attention. While I was conducting an interview with a group of healthcare practitioners at Sick Kids Hospital in Toronto, one of them said something that stuck with me: every time a person with diabetes checks their blood sugar, it's a reminder of their mortality.

I had never thought of it this way before, perhaps because the act has become so common place that I am no longer aware of its emotional effects. However, this brought to mind another memory. When I was in the final year of my undergraduate degree as a psychology major, I recall being in a personality disorder seminar where the prof explained to us that many people understand defense mechanisms such as denial incorrectly. While most people think that denial is a negative defense mechanism, he said, it is actually a vital component of our daily lives. If we actually walked around with an awareness of the statistical reality and our odds of dying at any given moment, we would not be able to function. Denial, then, is vital to our daily lives, and it's something we all engage in.

As I considered this in tandem with what the diabetes specialists at Sick Kids told me, I began to consider how every scan of the glucose meter, every blood test, every insulin injection, etc., are indeed a brush with mortality—a reminder that we are delaying the inevitable. We are “managing” diabetes, and the more I think about it, the more I think “management” is an interesting choice of word. When you ask someone how they are, and they say, “I’m managing,” the implication is that they aren’t doing great; they’re just staying afloat. In many ways, using the term “management” to describe the maintenance of an ideal stasis in the body for the purpose of prolonging a life that, by all organic measures, is already forfeit, rings similarly to me. There appears to be an unspoken consensus among the people

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I've interviewed that none of us are thriving in our bodies; we're managing—just keeping them afloat.

Journal Entry 6

During the interview, I was struck with an overwhelming sense of gratitude to the participants for their openness and willingness to discuss deeply personal and sometimes traumatic life experiences related to their illness (and sometimes not related to it!). However, I was also overwhelmed with gratitude for my own physical resilience, which is not something I really considered before. When you're chronically ill, you can't help but think of your body as at least a little bit defective, or perhaps as though there is something insufficient about it. You tend to view yourself as less resilient, less healthy, less able than other people, and none of those views are necessarily incorrect, but they are also relational. One of the themes that arose during interviews is the intense alienation that people with T1 diabetes feel. Many of us lack a community and we do not know many others with the illness. T1, one participant told me, is not a disease that breeds solidarity. I think she is right, and I think that this alienation can make it difficult for people with diabetes to understand their bodies and their health relationally, and I am no exception.

While doing my interviews, I met people who've had diabetes for far less time than I have and who've had far better "control" than I have yet experienced more complications or adverse physical symptoms than I have in my life. I met one woman eight years my junior who suffered from intense and painful neuropathy in her legs, which affects her mobility. She has had diabetes for 6 years, while I have had it for 18. I met another young woman who only graduated from university a handful of years ago and expressed feeling the effects of diabetes on her body, such as not being able to walk as far as she used to. This was all jarring for me. Aside from the mechanical demands of diabetes and the occasional bout of nausea that hits me when my blood sugars run extremely high, I have had no such physical effects on my body. I have only minor

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peripheral nerve damage in some of toes, which reduces sensation, but otherwise does not impact me. I get cavities maybe a bit more than the average person, and I have Non-Proliferative Diabetic Retinopathy that on my last eye checkup seemed to have cleared up. These are small inconveniences in comparison to some of the things my participants deal with, and hearing about their experiences shifted my perspective on my own health and able-bodiedness.

It reminds me of a particularly meaningful therapy session I had several years ago. My therapist at the time was not trained specifically for helping people cope with chronic illness, but I found her to be incredibly versatile and empathetic, so I was always happy to explain at length the ins and outs of diabetes. I told her that I still clung to a particular statement my pediatric endocrinologist had made when my blood sugars were out of control during my late teens. She'd said to me, "The cells remember," to emphasize that I was doing irreversible damage to my body. Of all the things I'd been told during those years, this was the one that wormed its way into my head and continues to affect me to this day. The statement ingrained a belief in me that I was a ticking time bomb that would inevitably blow. Implicitly, I started to believe that every instance of high blood sugar was cumulative, eliminating the possibility of healing.

During that therapy session, I remember saying that despite this belief, I knew that I couldn't have done any differently. I had to experience what I'd experienced in the manner that I had in order to overcome the emotional blocks that were preventing me from wanting to manage my diabetes. She suggested, then, that rather than thinking that I had been needlessly destructive to my body, I should try to remember that the destructiveness was inevitable, and to view my body as something that protected me until I was ready. I didn't fail my body; my body was there for me and supported me until I was ready to support it in turn. This completely reframed my relationship to my body; rather than the antagonistic relationship that diabetes had taught me to

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have with my body, I could instead understand our relationship as a partnership between two supportive halves of the same whole.

Journal Entry 7

I want to share the piece of writing that became the impetus for this project. In 2013, I was taking an anthropology course with Dr. Katie Kilroy-Marac, entitled Spectral Engagements. Late in the course, we read a book called *The Already Dead: The New Time of Politics, Culture, and Illness* by Dr. Eric Cazdyn. Our task for that week was to write a reading response to the book, but unlike previous weeks, I could only get through the first fifteen pages. After reading the book's introduction with great interest, my heart stopped on the first page of chapter one, entitled, "The New Chronic." Cazdyn writes:

We have entered something like a new chronic mode, a mode of time that cares little for terminality or acuteness. Every level of society is stabilized on an antiretroviral cocktail. Every person feels safe, like a diabetic on insulin."

Even after nearly a decade, those three sentences still make me pause. Now, in hindsight, I'd be remiss not to point out to Dr. Cazdyn that no diabetic ever feels safe, no matter how much access we have to insulin and other medical devices aimed at keeping us alive. Nonetheless, I want to share the reading response I wrote all those years ago because it is the heart of this project, and because I never want to forget what I felt on the day that I wrote it. It is a grim reminder of why I feel compelled to research emotional labour and T1 diabetes, and it is, if anything, one of many testaments to the complex interiority of those living with chronic illness.

For this week's reading my response will draw more upon personal experience, as I feel that *The Already Dead* speaks very deeply and directly to the conditions of my own life.

"Every person is safe, like a diabetic on insulin" (p. 13). I am a diabetic on insulin, and I have been so for the past eleven years. In reading this one sentence, I can't even articulate the

multitude of feelings that coursed through me. Since the first page of Cazdyn's book, I was on the edge of my seat because I am a person deemed chronically ill. But when that line about diabetics came up, the first thing that came to mind was, "Shit, I'm the already dead and new chronic, aren't I?" (though I hadn't read through the whole book at that point). The sentences that follow hit far too close to home:

A solid remission, yes, but always with the droning threat of relapse—of collapse, if not catastrophe, echoing back to us from a far-off future or from the memory of a distant past. So monotonous and stripped of urgency is this mode of experience that there is little reason to agonize, as long as the pain is managed and the possibility of any future change is repressed.

It reminded me of how much I hate hearing about potential "cures", because they never are actual cures—just more efficient ways of managing an incurable illness. More complex, increasingly expensive means that make me feel more and more like a cyborg every day. With all the money that goes into insulin pumps and blood glucose sensors, one would think there a way to figure out how to fix my stupidly faulty immune system. The state of diabetes research indeed leaves me in a state of repression—or perhaps suppression—over the dwindling possibility of a future without my condition. More than that, I hate navigating the space between outright dismissal and unnecessary pity from those around me. How can I explain to people that it is "no big deal" but that really, it *is* a big deal—just not in the way stage four brain cancer might be. I'm not dying, but I'm also not really living the way others do. I've found myself existing in a space of constant in-between-ness, perpetually grappling with the binary of health and disease. Can I be healthy and chronically ill? Regardless, the hope for a cure, in my view, is non-existent. I have always known that capitalism loves chronic illness, because as something that can be managed, it offers an irresistible opportunity to turn the sick into sources of capital. A diabetic spends hundreds of thousands of dollars on insulin, blood glucose meters, test strips, syringes, needles, etc. However,

what I never before considered was how this enterprise affects my sense of temporality and my relationship to time. Indeed, diabetes is ever present in my life, like a shadow that turns every corner the moment I do. But I also remember a time when I rebelled against diabetes, and when I tried to make it something acute and/or terminal—more so psychologically than physically. I chose to see it as a death sentence, and I refused to manage it. In hindsight, and ironically, I probably felt more hope then than I do now. I constantly ran up against my parents, my doctors, and the whole paradigm of healthy living. Neither the people in my life nor I could understand what exactly was driving this rebellion when the disease is, as we say for all chronic illness, 'perfectly manageable'. To tie this into last week's reading on depression, my doctors believed there had to be something innately wrong or twisted to motivate such self-destructive behaviour. Did I have an eating disorder? Was I depressed? There was an aggressive drive to label me with something that would make sense of what I was doing. But to my teenage brain, the idea of managing something for the rest of my life felt like more of a death sentence than actually dying of a disease that would naturally kill me anyway. There was an odd sense of pleasure in being able to say that something was killing me, and those who argued I could just manage it instead were ruining my buzz. And they would never let me forget it.

Interestingly, what I came to fear—which ultimately led me to managing my blood sugars after four years self-destructive non-management— was not death, but the potential decay of my body. This decay would never quite kill me, but leave me at the mercy of patch-work medical procedures like dialysis. Cazdyn argues that we have entered a new mode of time that traps us in an "undying present that remains forever sick, without the danger of sudden death". Regardless of my choice (to manage or not to manage), I would find myself in that undying present. And with it comes the maintenance of the status quo as the ultimate goal. It reminds me,

chillingly so, of my own experience with chronic illness, and how maintenance of a perpetual stasis is indeed the goal. The need to manage trumps the desire to cure, and this extends to our politics and culture. The idea of managing a manageable illness is common sense in our culture, and to suggest otherwise would likely land you in a therapist's office. It's a cultural truth that cannot be questioned.

Diabetes is a fascinating illness, even among the chronic, because it requires an active choice on part of the sufferer to manage it. Unlike other illnesses where things are done *to* the individual, diabetics must choose, on a daily basis, to do things to themselves. Unlike other chronic conditions like high blood pressure, which requires the habitual consumption of medication, diabetes demands that conscious choices be made—the right choices—in order to keep catastrophe at bay. Every minute of the day is measured. Management requires a kind of surrender to the illness; you have to allow your life to revolve around it, and every present moment must be dedicated to the disease, as though it too has agency and life that needs to be respected. Here, in the quintessential template for diabetes management, I see the glaring recipe for living constantly trapped in a present which extends into and eliminates the future. Ironically, then, the choice to not manage a chronic illness such as diabetes can constitute a resistance against this stagnant, endless present brought about by the internalized notion that it *must* be managed. Without management, multiple possible futures suddenly make themselves known, even if a fair number of them are painful and potentially devastating. Yet as mentioned earlier, most of these painful possibilities converge on a path that leads not to the terminal (death), but rather, to another state of the perpetual, undying chronic: hospitalization, invasive treatments, etc, that sustain the person's existence irrespective of where their body "wants" to go.

In his introduction to *The Already Dead*, Cazdyn plucks a line from Sigmund Freud's letter to Marie Bonaparte, which was written only two years before his death. At the time, Cazdyn explains, Freud was in a great deal of pain—both physically and psychologically—due to oral cancer and the Nazi advance into Austria. Freud wrote: “In order to find all of this bearable, one must remind oneself constantly that one really has no right to be living any longer” (from Cazdyn, 2012, p. 5). Cazdyn then challenges us to consider an inversion of Freud's statement: “in order to find the current moment unbearable, we must remind ourselves that we really have the right to die” (p. 5).

This is not an exercise in advocating for euthanasia or self-destructive impulses. Rather, it is about acknowledging and accepting that some things in life are truly unbearable. Our impulse, as a culture committed to health and longevity, is to reframe the unbearable as bearable—something Freud himself, the father of modern psychoanalysis—attempted. Cazdyn writes that this inversion is about “a certain relation to time, a relation to the present and the future, as well as the capacity to shape these temporal realities.” Acknowledging that we ought to consider bearable is, in fact, unbearable reframes the expectations that we place on the chronically ill to manage endlessly in the name of longevity but at the expense of something intangible. Participant 5 is an excellent example of the detriment the demand to make the unbearable bearable can produce. In the constant narrative that one with diabetes is just like everyone else and can do what anyone can do, the degree of immeasurable strength and resilience displayed by the person with diabetes becomes lost in a frenzied bid to render them normal and their condition bearable, when perhaps it would be more charitable, more compassionate, to acknowledge that there is something unbearable in the demand for constant control, and that they live with the unbearable makes them truly remarkable.

Appendix E: TCPS-2: CORE Certificate of Completion



Appendix F: Certificate of Ethical Approval



CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: 24238

Principal Investigator:

Ms. Alexandra Jocic, Graduate Student
Faculty of Health Disciplines/Master of Health Studies

Supervisor:

Dr. Karen Cook (Supervisor)

Project Title:

Type 1 Diabetes and Emotional Labour in Young Adults

Effective Date: February 25, 2021

Expiry Date: February 24, 2022

Restrictions:

Any modification or amendment to the approved research must be submitted to the AUREB for approval.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

A Project Completion (Final) Report must be submitted when the research is complete (*i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable)*) or the research is terminated.

Approved by:

Date: February 25, 2021

Barbara Wilson-Keates, Chair
Faculty of Health Disciplines, Departmental Ethics Review Committee

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Appendix G: Sample Interview Questions

1. When were you diagnosed with T1 diabetes?

Rationale: Although all participants should have lived with diabetes for at least two years, this question opens up the possibility to consider relationships between duration of illness and how the participant relates to their illness.

2. Did you experience any symptoms leading up to your diagnosis?

- a. How did your family respond?
- b. How did you feel about your symptoms?

Rationale: familial responses to symptoms may offer important insights into the kind of precedents being set in interpersonal dynamics. These early dynamics may in turn inform how the participant coped with their illness following diagnosis.

3. Tell me about the day you were diagnosed/the lead-up to diagnosis.

- a. How long did it take to get a diagnosis?
- b. How did you feel throughout the process?
- c. What went through your head when the doctor told you that you have diabetes?
- d. How did your family react?
- e. Did you tell anyone when you found out? Why or why not?

Rationale: This series of questions is intended to explore the emotional precedents established during and immediately after diagnosis. The key conversations and emotional journeys of participants during the earlier course of their illness may set the tone for later coping mechanisms. Furthermore, it may reveal how, where, and to what degree participants were expending emotional labour.

4. Describe living with diabetes in three words.

Rationale: This question forces the participant to be selective about how they want to describe their experience. In doing so, they must choose the words that most deeply resonate. This in turn may reveal significant insights into their relationship with diabetes.

5. How would you describe yourself on your best days and your worst days?

Rationale: Because diabetes is managed on a daily basis and requires constant blood glucose monitoring and navigating complicated social dynamics, participants may feel that their relationship to the illness depends the success of these aspects of management and socialization. The discrepancy between ‘good days’ and ‘bad days’ may offer insight into how, when, and why emotional labour is expended or over-expended.

6. When I use the term “emotional labour” what is your response? Reaction?

Thoughts? Feelings?

Rationale:

7. Have you ever heard the term emotional labour before? In what context?

Appendix H: Participant Definitions of Emotional Labour

Participant 1 [P1] described emotional labour as, "...the behind-the-scenes work that goes into having diabetes. Not the physical injections...but preparing for everything and thinking [about] all those decisions." She noted having heard the term in discourse on gender.

P2 interestingly used the terms *emotional labour* and *emotional burden* interchangeably throughout the interview, indicating that she understood *emotional labour* to be a kind of obligatory burden associated with living with diabetes. She further elaborated that she associated the term *emotional labour* with "the emotions that we [people with T1 diabetes] might feel that people without T1 don't feel—the excess, the add-ons."

P3 associated the term with what I have called cognitive labour: "the thought process that goes behind [diabetes]...how much you actually have to put into it mentally." P3 had also heard the term used in healthcare settings, specifically in relation to chronic pain. She was also familiar with the term's use in discourse on division of domestic labour, especially in domestic partnerships.

P4 said her first association with the term was having to educate people about her diabetes and the work that goes into managing blood glucose. Thus, her primary association was that of a social dynamic, though she added that she could "see it also being the emotional toll of managing [diabetes], day in and day out."

When I asked P5 about her association with the term *emotional labour*, she told me that she felt as though people with T1 diabetes have an entirely different emotional experience than those without it. She described having T1 as a full-time job, then continued in a similar vein to P2: "To me, it's the emotional weight that [diabetes] occupies. When I hear emotional labour, that's the first thing that comes to mind."

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P6 understood emotional labour primarily through the lens of marginalization and associated the term with women of colour, queer people, and people with disabilities. Her sentiments echoed Kelly et al. (2019) and P4; she too mentioned associating the term with having to educate people who may not understand how marginalization impacts the ways in which people move through the world, and the precautions marginalized people must take to remain safe. Furthermore, she associated the term with having to explain her traumatic experiences to others.

P7 was perhaps the least familiar with the term and said she had only started hearing it recently. She associated it with mental health and the burdens that accompany living with mental health challenges, as well as Diversity, Equity, and Inclusion spaces.

P8's association was closest to the original definition offered in *The Managed Heart*. She said to me:

When you work in retail, you have to smile and be friendly...these things where you have to perform or behave in a certain manner to get stuff done, [but] people don't act like it's a burden or a thing you have to do.

As with many of the other participants, P8's understanding of emotional labour was linked with performativity and protecting the comfort of a hegemonic group, as well as with popular discourse on the division of domestic labour.

Finally, P9 associated the term with her experience of diabetes as a draining illness. She elaborated, "It's the times you wish you didn't have it or don't want to deal with it, but still do. Can't not." Interestingly, P9 associated *emotional labour* with planning her life around diabetes. During her university exams and prior to diagnosis, she was concerned that the invigilators would think she was cheating if she used the bathroom too frequently (a common symptom of

diabetes), so she scheduled her bathroom breaks before, during, and after the exam. For P9, then, *emotional labour* was associated with both mental labour (i.e., scheduling, planning), and the kind of performance established by Kelly et al. (2019) (i.e., managing the perceptions of the exam invigilators).