

PSYCHOSOCIAL EXPERIENCES OF TYPE 1 DIABETES DIAGNOSED IN EMERGING
ADULTHOOD

by

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Abstract

While advances in medical technology have enabled people with type 1 diabetes (T1D) to live longer lives with fewer complications, these interventions are only as effective as individuals' abilities to implement them. People diagnosed during emerging adulthood (i.e., ages 18-30) face high risk of poor health outcomes, as they must attempt to balance the demands of chronic illness with mastery of normative life tasks, namely identity exploration and development. To better understand the unique needs of this population, the present study investigates the lived experiences of people diagnosed with T1D during emerging adulthood. Interpretive phenomenological analysis (IPA) was used to elucidate the accounts of four participants with T1D, and to develop a more general description of this shared phenomenon. Data were analyzed for hierarchical themes, and are presented alongside verbatim quotes from interview transcripts to substantiate researcher interpretations. This thesis research argues for the inclusion of counsellors in routine diabetes management, to address the psychological, social, and spiritual aspects of health that are currently neglected by mainstream medicine, and that interfere with successful disease management.

Preface

This thesis is an original, intellectual work by the author, Tanya Annalise Jakobsen. The research project was conceptualized, developed, and conducted by the author under the supervision of Dr. Colleen Haney and Dr. William Borgen, with support from committee member, Dr. Marv Westwood. Original ethical approval for this study was issued by the University of British Columbia Behavioural Research Ethics Board on February 17, 2015 (Certificate H14-03258).

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Dedication

This thesis research is dedicated to the countless young adults confronted by chronic disease diagnoses in the midst of creating themselves and their dreams for life. Special thanks to the generous participants who shared their stories for the purposes of this research, each unexpectedly diagnosed with type 1 diabetes between the ages of 18 and 30.

I would also like to personally dedicate this work to my parents, Ole and Jennifer, and my husband Adrian, for their faithful support in all my endeavours, academic or otherwise.

CHAPTER 1: Introduction

Study Rationale

The present study examines the lived experiences of men and women diagnosed with type 1 diabetes (T1D) during the stage of life known as emerging adulthood, which spans ages 18 to 30. Admittedly, I was ignorant to the need for such research until 2012, when at the age of 24 I too was unexpectedly diagnosed with this autoimmune disease. The World Health Organization describes diabetes mellitus as a full-fledged, global epidemic, and its consequences are pervasive (WHO, 1999). This chronic illness jeopardizes health, poses financial hardship, and constitutes crises at the personal and population levels.

While advances in medical technology have enabled people with T1D to live longer lives with fewer complications, these interventions are only as effective as individuals' abilities to implement them. This is especially critical for emerging adults, who face increased risks of psychological comorbidities that interfere with successful disease management (e.g., depression and eating disorders) (Chiang, Kirkman, Laffel, & Peters, 2014). Newly diagnosed emerging adults are tasked with balancing the demands of a life-altering disease, with the normative life tasks of this developmental stage.

Researchers argue for the inclusion of counsellors in routine diabetes management, in an effort to address the psychological, social, and spiritual aspects of health that are currently neglected by mainstream medicine's biomedical model (Roberts, Kiselica, & Fredrickson, 2002). However, before we can determine which topics to address in counselling, or design developmentally sensitive interventions for this demographic, we must first understand the actual experiences of these individuals. This exploratory, qualitative study uses interpretive

phenomenological analysis to elicit and understand individuals' subjective experiences of life with T1D.

The present research contributes to the foundation upon which health care professionals can develop resources and interventions, tailored to the growing number of emerging adults diagnosed with T1D. Research findings may interest a variety of clinicians (e.g., counselling psychologists, endocrinologists, and nurse educators) and people with diabetes alike, as competent care is a shared responsibility. Results can help counsellors and other health professionals better understand how T1D influences each client's embodied, lived experiences and meaning-making processes. This can help clinicians to develop and continually adapt individualized treatment plans that incorporate interventions and services that meet clients' changing needs across the life span.

This introductory chapter begins with a description of diabetes mellitus and its far-reaching impacts, before providing a review of the literature, and substantiating the need for this research. The chapter ends with a discussion of the research question that orients this study.

What is Diabetes?

Diabetes mellitus (DM) is a disorder of metabolism, disrupting the way that the body uses digested food for growth and energy (Joshi & Mukhopadhyay, 2014). During digestion, most of the food that people consume is broken down into a type of sugar called glucose, which constitutes the body's primary source of fuel. However, as glucose passes through the bloodstream, beta cells in the pancreas must produce a hormone called insulin, to allow glucose to enter cells and be used as energy. In people with DM, pancreatic beta cells either produce no insulin, not enough insulin, or their bodies become resistant to the insulin produced and cannot

utilize it properly. As a result, glucose accumulates in the bloodstream, overflows into the urine, and is eventually expelled from the body. This deprives the body of its essential source of energy, despite large amounts of glucose circulating in the bloodstream.

Furthermore, the excess blood glucose damages organs, blood vessels, and nerves, contributing to debilitating long-term complications such as heart disease, stroke, kidney failure, and retinopathy (de Faria Maraschin, 2012). DM can cause acute complications including diabetic ketoacidosis, which results when the body burns fatty acids as an alternate energy source and acidic ketone bodies accumulate as a byproduct. Additional adverse reactions include nonketonic hyperosmolar coma, a condition characterized by severe dehydration that ensues when excess fluid is drawn from the body to flush out glucose in the urine. Ultimately, without appropriate medical intervention, DM can result in premature death (Imam, 2012).

Since Egyptian physician, Hesy-Ra first documented a list of remedies thought to combat the passing of excess urine circa 1500 BC, significant advancements in the treatment and classification of DM have been made (Zajac, Shrestha, Patel, & Poretsky, 2010). Prior to the discovery of insulin, DM treatment was limited to starvation diets intended to minimize sugar intake. The discovery of insulin in 1921, by Canadian surgeon, Frederick Banting, and his assistant, Charles Best, marked the final step in identifying the substance whose deficiency triggered the onset of DM (Zajac et al., 2010). Insulin therapy is not a cure, yet its introduction changed the prognosis of DM, and the quality of life for people affected by the disease.

Type 1 Diabetes

DM is now thought to represent a heterogeneous group of conditions that share certain characteristics, with elevated blood sugar as a common feature (de Faria Maraschin, 2012).

Modern, pathogenesis-oriented classification of DM cases has increased clinicians' ability to distinguish numerous variations in presentation. While much remains unknown about newer forms of DM (e.g., latent autoimmune diabetes of adults, and maturity onset diabetes of the young), the two predominant categories are type 1 and type 2 diabetes. A discussion of distinctions in epidemiology and clinical presentation is beyond the scope of this paper, as the present study seeks solely to elucidate the impact of T1D on individuals' lives.

T1D is an autoimmune disease that results when a person's immune system mistakenly attacks and kills the pancreas' insulin-producing beta cells (Canadian Diabetes Association, 2014). This means that no, or extremely little insulin is naturally released in the body. At present, the exact cause of T1D remains unknown, and there is no cure. Due to the frequency of diagnosis in children, T1D was formerly known as juvenile diabetes but is now understood to develop at any age (Chiang et al., 2014). In order to prolong the life span and minimize complications, current treatments require people to monitor their blood glucose frequently, rely on multiple daily insulin injections or insulin pump therapy, and pay careful attention to diet and physical activity. Regardless of subtype, DM jeopardizes population health, burdens national economies, and creates personal crises for millions of people across the globe.

CHAPTER 2: Literature Review

Impact of Diabetes

In 2011, DM was thought to affect 366 million people worldwide, a number expected to reach 552 million by 2030 (Whiting, Guariguata, Weil, & Shaw, 2011). As of 2009, approximately 2.4 million Canadians were living with DM, an additional 700,000 remained undiagnosed, and over 20 new cases were being diagnosed every hour (CDA, 2009). The economic burden of diabetes in Canada was expected to reach \$12.2 billion in 2010 and the direct cost of DM has now surpassed 3.5% of the national, public healthcare expenditure. Unless a cure is found, DM will likely affect 9.9% of the Canadian population by 2020, and cost the country a projected \$16.9 billion dollars.

More specifically, T1D accounts for 5% to 10% of all DM cases (American Diabetes Association, 2009), and its incidence is increasing 2% to 5% each year (Maahs, West, Lawrence, & Mayer-Davis, 2010). An estimated 300,000 Canadians are currently living with T1D, costing each as much as \$15,000 in direct, out-of-pocket medical expenses each year (CDA, 2009). Despite its historical connotation as a childhood disease, the majority of people with T1D are adults (CDA, 2009; Miller, Secrest, Sharma, Songer, & Orchard, 2012). This can be attributed to the increasing life expectancies for individuals diagnosed as children, combined with the rise in number of cases diagnosed in adulthood (Miller, Secrest, Sharma, Songer, & Orchard, 2012). The exact incidence of new-onset, T1D in adults remains unknown. However, an estimated 25% of cases are diagnosed in adulthood (Haller, Atkinson, & Schatz, 2005). In addition to causing significant financial burden, a chronic illness diagnosis initiates profound change in a person's

life, and typically poses deleterious effects on quality of life and wellbeing (Sprangers et al., 2000).

Among the most challenging consequences of DM are its physical implications. The life expectancy for people with T1D is reduced by up to 15 years, as DM leads to and worsens a variety of critical conditions. The Canadian Diabetes Association (CDA, 2009) reports that approximately 80% of Canadians with diabetes die from heart attack or stroke, and that almost half of new patients starting kidney dialysis have DM. In Canada, DM is the leading cause of blindness, and also accounts for 70% of non-traumatic limb amputations.

Doctors typically prescribe rigorous courses of treatment that combine medication and lifestyle adjustments, to delay long-term complications and death. However, ambulatory stabilization has replaced hospitalization as the initial point of care for most newly diagnosed adults, limiting their opportunities to adjust to the disease while under the constant supervision of experienced clinicians (Dunn et al., 1994). This means that people confronted with what is likely among the most traumatic and life-altering events of their lives, must understand and implement technical information rapidly, change established behavioural patterns, and assume responsibility for self-management of the disease immediately (Beeney, Bakry, & Dunn, 1996; Roberts et al., 2002). When receiving a chronic illness diagnosis Pollin (1995) posits that people deeply crave acknowledgement that "life has been stood on its head" (p. iv). Without the opportunity to integrate this trauma, treatment adherence and quality of life suffer.

While diabetes researchers are developing technologies that enable people with T1D to live longer lives with fewer medical complications, these treatments can only be as successful as the ability of the individual to implement them (Chiang et al., 2014). However, the traditional

biomedical model does not address health holistically, and fails to adequately attend the psychological and social impacts of chronic illness, that interfere with successful treatment (Roberts et al., 2002). Consequently, in the urgency to impart patients with the information and skills necessary for effective self-care, it is critical that their psychological needs are not neglected (Beeney et al., 1996).

Need for Counsellors in Disease Management

Roberts et al. (2002) argue for the inclusion of psychological counselling as a vital component of routine disease management. As medical technologies have advanced, once fatal diseases have become chronic illnesses that allow people to live longer lives, albeit with some complications. As the negative effects of disease evolve, increased attention must be paid to emotional, social, and spiritual aspects of lifestyle adjustment, in order to bolster people's capacities to cope effectively.

As an alternative to the traditional medical model, Roberts et al. (2002) suggest that a biopsychosocial model of health and wellbeing be adopted. Among its reported strengths is the model's acknowledgement of reciprocal interactions between the biological, psychological, social, and spiritual dimensions that influence overall health. The authors credit the traditional medical model for making tremendous progress toward curing disease and mitigating suffering, but recommend that psychosocial intervention be introduced, adjunct to medicine, in order to treat the whole person. Counsellors are excellent candidates for this responsibility, complementing medical regimes to deliver more comprehensive health services.

Evidence supporting the inclusion of counselling in the treatment of chronic disease, includes studies demonstrating that positive prognostic outcomes can result when people's

psychological states are addressed in conjunction with their medical conditions (Roberts et al., 2002). For example, Silverstone (1990) reports that the presence of depression in people with life-threatening illnesses predicts poorer health outcomes. Of the 211 participants studied, almost half of those with depression suffered serious complications or died, compared with only 10% of participants without depression.

Moreover, research from the field of psychoneuroimmunology demonstrates that the immune system's natural ability to heal the body is dependent, in part, on the mental processes that people experience as thoughts and feelings (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002). In one study, Levenson and Bemis (1995) found that adjustment level, lack of social support, fatigue, and depressive symptoms, accounted for 30% of the variance in natural killer cells (those able to destroy malignant cells) among people with cancer.

Research also demonstrates that emotional problems can decrease people's compliance with doctors' recommendations for disease management (Sprangers et al., 2000). For people with diabetes, this is particularly important information, as the condition is associated with a variety of psychological comorbidities, among which depression and eating disorders are the most prominent. A meta-analysis of 39 studies with a combined participant pool of over 20,000, estimates that having diabetes makes people twice as likely to exhibit depression than their non-diabetic counterparts (Lustman, Anderson, Freedland, de Groot, & Carney, 2000).

In Jones et al.'s (2000) multisite study of 356 females aged 12-19 and 1098 case-matched controls, prevalence rates of full syndrome and sub threshold eating disorders among adolescent and young adult women with T1D, were two times higher than among their non-diabetic peers. Given that an estimated 25% of Canadians with DM also suffer from depression and that eating

disorders dramatically increased the likelihood of major complications, these data highlight the importance of addressing psychological issues adjunct to physical ones (CDA, 2009; Jones et al., 2000).

While the inclusion of counsellors in routine management of T1D is a relatively novel concept, a growing body of literature already demonstrates its efficacy in the treatment of cancer. Results from two meta-analyses, reviewing a total of 82 studies, clearly confirm that psychosocial interventions delivered by counsellors, have a positive impact on quality of life for adults with cancer (Meyer & Mark, 1995; Rehse & Pukrop, 2003). Moreover, Rehse & Pukrop report that overall effect size was moderated by several variables. Among the most salient is duration of intervention, as those lasting 12 weeks or more, were significantly more effective than short-term approaches. The authors suggest that the quality of client-therapist relationship is integral to counselling's success, and a fruitful relationship takes time to build.

A recent position statement of the American Diabetes Association acknowledges the psychological issues that have been largely overlooked in diabetes care, and prescribes multidisciplinary teams, specialized training, and individualized care plans to address this service gap. For counsellors to be equipped for careers in healthcare, education programs must help trainees understand the biological foundations of chronic illness, develop multicultural competence, and become sensitive to the traditional medical treatment process, in addition to typical curricula (Chiang et al.; Roberts et al., 2002). Medical professionals must also be willing to enter mutually respectful relationships with counsellors to ensure a more holistic, therapeutic, encounter for each client. Chiang et al. attest that all patients need individualized care plans, continued education and support, and ongoing assessment to address potential complications.

Ultimately, as people and T1D cases evolve, therapeutic approaches must be modified to meet individuals' disparate and changing needs.

Emerging Adults: A Neglected Demographic

Due to T1D's early conception as a disease exclusive to children, the unique needs of people diagnosed in adulthood have been neglected. Newly diagnosed adults need resources and supports to understand and adjust to their condition, but most available resources are geared toward children and their parents. Children's developmental stages are well documented, and interventions for T1D have been tailored to the needs of children at different ages and growth stages (Chiang et al., 2014). The life stages navigated in adulthood are more ambiguous and underappreciated, making it difficult for newly diagnosed adults to find age-appropriate resources and supports.

In 2000, Arnett differentiated a stage of adulthood he coined, emerging adulthood. Spanning the late teenaged years through the twenties, emerging adulthood is wedged between adolescence and adulthood. Emerging adults have typically abandoned the dependency characteristic of childhood and adolescence, but have not yet accepted the enduring responsibilities typical of adulthood. This life stage is characterized by identity exploration and development, providing opportunities to experiment with possible directions in regards to relationships, careers, and worldviews. However, it is important to note that life stages are cultural constructions and are neither universal nor immutable. This means that not all cultural groups, or individuals within these groups, will behave as Arnett describes between the ages of 18 and 30.

While assessment of potential psychosocial issues is important for people with T1D

irrespective of age, emerging adults face unique challenges and are at high risk for negative health outcomes. Chiang et al. (2014) delineate a variety of areas relevant to emerging adults that have not been adequately addressed in the existing literature. Receiving a T1D diagnosis during this critical period of identity formation may lead people to neglect their disease management, normative life tasks, or both. In order to mitigate such negative effects, Chiang et al. espouse the importance of exploring the impact of a T1D diagnosis on the following themes characteristic of emerging adulthood: identity formation, development of personal meaning, social and romantic relationships, conception, career search and maintenance, travel, financial responsibilities, involvement of family and friends, and coping strategies.

In addition, emerging adults are reportedly more prone to developing subclinical or clinical depression, fears of hypoglycemia and hyperglycemia, eating disorders, and insulin omission, than other age groups (Chiang et al., 2014). These issues strongly correlate with poor diabetes self-management, higher incidence of complications and reduced quality of life. While emerging adults face distinct challenges, they are thought to have greater knowledge, experience, literacy, numeracy, and cognitive abilities than children, and older adults. This makes it especially important for clinicians to understand the issues and concerns of emerging adults diagnosed with T1D, while tailoring treatment to leverage their assets.

Research Question

Researchers identify the critical need to improve psychological adjustment in people diagnosed with T1D, and call for studies involving age and cultural groups that have been neglected in the literature (Enzlin, Mathieu, & Demyttenaere, 2002; Beeney et al., 1996). Guided by these suggestions, the present study focuses on people diagnosed with T1D in emerging

adulthood. However, before we can determine which topics to address in counselling, or design developmentally sensitive interventions that improve holistic health outcomes for this demographic, we must first understand the actual experiences of these individuals. The research question that naturally emerges is:

What are the lived experiences of people diagnosed with type 1 diabetes in emerging adulthood?

CHAPTER 3: Methodology

This chapter introduces the research framework that guides the present study, exploring its theoretical foundations before delineating the strengths and limitations of the chosen approach. A discussion of study procedures and practical considerations concludes this section.

Interpretive Phenomenological Analysis

Guided by its theoretical basis, and supported by current research, the present study's research question dictates an inductive, qualitative methodology. Interpretive Phenomenological Analysis (IPA) is an apt choice, as it examines how individuals experience and understand a particular shared phenomenon. Introduced by Smith (1996), this method represents an effort to integrate experiential approaches into mainstream psychology research. IPA views people as sense-making creatures, and prompts participants to reflect on their life paths and associated choices. It seeks to uncover the subjective meanings attributed to embodied, cognitive-affective, and existential aspects of experiencing, rather than dwelling exclusively on cognitions. IPA's framework for research lends itself to exploratory inquiry, asking open-ended questions that emphasize personal meaning, rather than objective outcomes (Finlay, 2011; Smith & Osborn, 2008). It is also well suited for studies of illness experience, and has been recommended for use in the field of counselling psychology (Clarke, 2009).

Theoretical Foundations. Finlay (2011) summarizes three essential features that distinguish IPA from other research methodologies: (a) phenomenological roots, (b) a hermeneutic approach, and (c) an idiographic orientation. A discussion of these features follows, elucidating IPA's theoretical underpinnings, and their applications to research.

Phenomenology.

Husserl. IPA endeavors to explore individuals' perceptions of particular events or states, rather than intending to produce an objective account of these phenomena. This central tenet echoes the founding principle of phenomenological inquiry: experience should be examined in the manner it occurs, and in its own terms (Smith, Flowers, & Larkin, 2009). Husserl originally conceptualized phenomenology in an effort to construct a philosophical science of consciousness, and it has since been developed by authors in the fields of philosophy and psychology.

Husserl was primarily concerned with the careful examination of human experience, and sought a means by which one might come to accurately know one's own experience of a phenomenon (Smith et al., 2009). When conducted with a certain depth and rigour, this inquiry was expected to illuminate the essential qualities of a particular experience. Husserl posited that these essential features could transcend individual circumstances, shedding light on others' experiences of the same phenomenon. Husserl came to believe that individuals' direct experiences of life are the fundamental source of knowledge (Dowling, 2007).

However, Husserl recognized that the human predilection for order motivates people to fit phenomena into their preexisting mental systems of categorization, or "natural attitudes" (Smith et al., 2009). Inevitably, these systems shape one's understanding of an experience, rather than allowing each particular phenomenon to be examined its own right. Husserl urges people to step outside of their natural attitudes, and to adopt "phenomenological attitudes" instead. This involves shifting one's attention from phenomena in the world, towards one's inward perceptions of these phenomena. A phenomenological attitude requires one to disengage from the activities

of daily life, focusing instead on the "taken-for-granted" experience of the world. Husserl also introduces the concept of "intentionality" to describe the relationship between processes occurring in consciousness, and the object of attention for those processes (Smith et al., 2009). Thus, consciousness always implies consciousness of an object; there is an intentional relationship between experience, and the object to which this experience is oriented.

The aforementioned concepts were united in Husserl's early approach to a phenomenological method. First, he prescribed attending the taken-for-granted experience of one's activities in the familiar world. Next, the consequences of these taken-for-granted ways of living must be considered. Husserl advocated the use of "bracketing", which refers to the process of putting aside one's taken-for-granted world, in order to focus on one's perceptions of that world (Dowling, 2007). Bracketing is achieved through a series of reductions intended to move the individual away from the distraction of preexisting assumptions, and towards defining the essence of experiencing a particular phenomenon. This reductionist perspective posits that the essence of a phenomenon can be understood by isolating a person's immediate conscious experience of the phenomenon, before any reflections or interpretations are imposed (Dowling, 2007).

Husserl considered science a second-order knowledge system, and was opposed to its privileged knowledge claims (Smith et al., 2009). He contended that such claims depend on first-order personal experiences, and that the taken-for-granted aspects of experiencing, or "lifeworld", provide the grounding for a so-called objective, scientific world. Husserl aimed to lay the foundations of a more authentic science, and disproved of the psychology discipline identifying as a natural science. As a philosopher and not a psychologist, Husserl's work was

predominantly conceptual, and concerned with generic processes. His writings focused on the experience of phenomena for self, not others. Concepts were later adapted and extended for application to psychological research investigating the experiences of others. While IPA draws on foundations of Husserlian phenomenology in that it seeks to understand the lived experiences of individuals, it deviates from Husserl's epistemology in the salient ways discussed next.

Heidegger. Originally a student of Husserl, Heidegger moved away from the transcendental phenomenology of his predecessor, and laid the groundwork for hermeneutic and existential branches of phenomenology (Smith et al., 2009). He was concerned with the mysteries of existence itself, the practical activities and relationships that humans are caught up in, and how the world appears and is made meaningful through the unique lenses of humans' situated experiences. Heidegger questioned the potential for knowledge devoid of interpretation and grounding in the lived world of objects, people, relationships, language, and culture. He asserted that consciousness makes possible a significant world, in which meaning is of central importance.

In his seminal work, *Being and Time* (1962/1927), Heidegger introduces the concept of "Dasein". Literally translated as "there-being", Heidegger chose this term to embody the situated quality of "human being". Dasein represents Heidegger's belief that people are "already always" thrown into a preexisting world of objects, relationships, and culture, and cannot be meaningfully detached from this context. Heidegger describes Dasein as being-with, suggesting that even being alone is evidence for the existential requirement of others: "Being alone is being with in the world. The other can be missing only in and for a being with. Being alone is a deficient mode of being with; its very possibility is proof of this" (pp. 156-157).

Central to this notion is the view that each human being is a person-in-context, and the concept of "intersubjectivity". This term refers to the shared, relational, and often, overlapping nature of human engagement in the world, uniting what is possible, with what is meaningful. Heidegger uses intersubjectivity to reflect the quality of relatedness-to-the-world that is an innate part of the human condition, and to explain our capacity to communicate and make sense of one another.

Heidegger's work influences IPA in three primary ways: (a) human beings can be conceived as thrown into a world of objects, relationships, and language, (b) a human's being-in-the-world is always perspectival, time-based, and oriented towards something, and lastly, (c) the interpretation of human beings' meaning-making processes is fundamental to phenomenological inquiry in psychology (Smith et al., 2009).

Merleau-Ponty. Merleau-Ponty subscribes to Heidegger's concept of being-in-the-world, and calls for a more contextualized phenomenology. Though Merleau-Ponty agreed with Heidegger's understanding of knowledge's situated, interpretive character, he diverged from Heidegger's emphasis on worldliness. Instead, Merleau-Ponty examined the embodied nature of humans' relationships towards their world, emphasizing that humans cannot escape the primacy of their own situated worldviews (Smith et al., 2009). He believed that human beings see themselves as distinct from everything else in their world, and that empirical science does not adequately conceptualize human mechanisms of perception and judgment. Merleau-Ponty introduced "body-subjects", as the embodied nature of humans' relationships to the world. He explains that, "the body [is] no longer conceived as an object in the world, but as our means of

communication with it" (Merleau-Ponty, 1962, p. 106). Moreover, the physical body is seen as the meeting point between self and world.

Merleau-Ponty (1962) suggests that subjectivity and embodiment intersect when people think about how they see one another. While a human being can experience and express empathy towards another, he can never share the other person's experience fully, as the experience belongs to the other's own embodied position in the world. Consequently, the intentional nature and meaning of the ownership and content of experience are always personal to the body-subject. IPA draws on this view, affirming that the physical body shapes the fundamental quality of our knowing about the world (Smith et al., 2009).

Sartre. Sartre (1956/1943) extends our understanding of existential phenomenology, determined that people are caught up in projects of the world. He believes that the human capacity to make meaning, and the ability to be self-conscious, are action-oriented processes that engage with the world. Sartre emphasizes the developmental nature of human being. He uses the phrase, "existence comes before essence," to describe the continual human process of becoming oneself (Sartre, 1948, p. 26). This self is considered a project that unfurls, rather than a preexisting entity to be discovered in full.

Sartre saw things that were absent as equally important to things that were present, in defining a person, and how that individual views the world (Smith et al., 2009). The presence or absence of something was thought to fix the meaning of a particular context, at a particular point in time. Sartre expands this view to the social, interpersonal world, describing the presence of another as a marker around which perceptual features of an environment are organized. This presence prevents the perceiver from experiencing the environment in its own terms. This

influence is reciprocal, as the awareness of being perceived by another triggers self-consciousness, impacting subsequent perceptions and meaning-making (Smith et al., 2009).

IPA draws on Sartre's extension of "worldliness", into the social realm. This work considers the conception of experiences as contingent upon the presence or absence of one's relationship to others (Smith et al., 2009). IPA is also influenced by Sartre's acknowledgement of people as engaged in projects in the world, and his emphases on the embodied, interpersonal, affective, and moral aspects of these experiences.

Ultimately, Husserl's phenomenology established the importance of focus on individual experience and its perception. Subsequently, Heidegger, Merleau-Ponty, and Sartre offered unique perspectives on the view that human beings are embedded in a world of projects, objects, relationships, language, and culture. These authors express a complex view of experience, one that focuses on lived processes and evolving perspectives and meanings, that are unique to a person's embodied, situated relationship to the world.

IPA attempts to convey particular phenomena, as experienced for particular people, and focuses on interpretations and attempts to make meaning out of events and action. Nevertheless, in the present study access to a participant's world depends upon the researcher's own interpretive thought processes to make sense of the participant's subjective world (Smith et al., 2009). For this reason, we now turn to a discussion of hermeneutics, the theory of interpretation itself.

Hermeneutics. Hermeneutics is concerned with the methods and purposes of interpretation, and developed in an effort to provide more reliable foundations for the interpretation of biblical texts (Smith et al., 2009). It has evolved into a philosophy guiding the

interpretation of a wide range of texts including historical documents, literature, and testimony. The discipline questions whether it is possible to reveal the original meanings intended by a text's author, and considers the nature of the relationship between the context of a text's production, and the context of its later interpretation.

Schleiermacher. At the turn of the 19th century, Schleiermacher initially wrote about hermeneutics as a generic form. He viewed interpretation as comprised of grammatical interpretation, referring to the objective meaning of the text, and psychological interpretation, referring to the individuality of the author (Schleiermacher, 1998). Schleiermacher's holistic perspective of interpretive process held that a text is influenced by conventions of the author's linguistic community, in addition to the author's individual treatment of the language. He determined that the unique intentions and techniques of the author impress upon the text, a very specific meaning, and that the aim of interpretation, is to understand the author as well as the text (Smith et al., 2009).

Schleiermacher (1998) believed that the relationship between the interpreter and the text's original author provides a perspective on the text that the author is unable to access. In IPA, this does not mean that the researcher's analysis is more true than a participant's account, but that analysis can offer meaningful insight beyond the account's explicit content (Smith et al., 2009). Schleiermacher viewed interpretation as an art involving intuition, not simply a series of mechanical rules to abide. The value IPA adds to a text comes in part, from connections made possible by having access to the larger data set, and through links to psychological theory. However, effective interpretation depends upon every person's receptiveness for all others, and a

spirit of openness (Schleiermacher). This insight foreshadows phenomenological philosophy's subsequent focus on intersubjectivity.

Heidegger. Hermeneutics intersects with our earlier discussion of Heidegger's contributions to phenomenology, in his efforts to build a case for a hermeneutic phenomenology. Heidegger identified an element of personal engagement believed to be present in all interactions, leading people to qualify some phenomena as more meaningful than others (Wilding & Whiteford, 2005). The attribution of subjective value is thought to form the foundation upon which individuals interpret and make sense of their life experiences.

Heidegger explains that access to human beings' situated contexts, or *Dasein*, always occurs through interpretation (1962/1927). Heidegger highlights the dual character of appearances, delineating visible meanings, and hidden, latent meanings. It is this interplay of meaning that phenomenology is concerned with, as manifest appearance is inherently connected to deeper latent form (Smith et al., 2009). Heidegger continues, stating that interpretation rests upon "fore-ception", which includes prior experiences, and assumptions. As a person interprets a new phenomenon, it is inevitably considered in the light of prior experiences. This organization of presuppositions, or "fore-structure" can present a barrier to interpretation if it is given precedence over the new phenomenon. However, Heidegger offered insight that motivates a reevaluation of Husserl's bracketing, when it comes to interpreting qualitative data.

Heidegger believed that while one's fore-structure may exist prior to encountering a new phenomenon, this phenomenon may elicit a better understanding of one's fore-structure (Smith et al., 2009). For example, once a researcher has engaged with the data, the researcher has a better vantage point from which to determine which parts of the fore-structure are relevant to

interpretation. IPA affirms the explicitly interpretive nature of phenomenology, and advocates a continual, iterative process of reflection upon a phenomenon, the researcher's fore-structure, and the evolving relationship between the two. In this view, bracketing can only ever be partially achieved, thus it is not a central goal of IPA.

Gadamer. Gadamer builds on the work of Schleiermacher and Heidegger, in his work concerning the analysis of historic and literary texts. In his influential work, *Truth and Method* (1990/1960), Gadamer focuses on the significance of history, and the influence of tradition on interpretive process. He agrees with Heidegger that preconceptions can be better understood as interpretation is underway, rather than attempting to bracket prematurely. Gadamer viewed the quest to understand the meanings of a text as a continual process of new projections.

Conceptions are triggered as meaning is unearthed, and the interpreter compares, contrasts, and revises these beliefs throughout the sense-making process (Smith et al., 2009). In this way, the text influences interpretation, the interpretation influences fore-structure, which, in turn, influences interpretation. Gadamer equates the interpretive process, moving between preconceptions and the text itself, to engaging in a dialogue between past and present. In the effort to understand a text one must let the passage speak its voice, maintaining awareness of preconceptions that can deter this aim. From Gadamer's perspective, a spirit of openness is essential to effective interpretation.

Consistent with hermeneutic phenomenology, IPA assumes that it is impossible to gain direct, unbiased access to others' experiences, as a researcher's own experiences, values, and assumptions interact with all information collected. Smith and Osborn (2008) identify this practice as a double hermeneutic, whereby "the participants are trying to make sense of their

world, [and] the researcher is trying to make sense of the participants trying to make sense of their world" (p. 53). Instead of solely describing a phenomenon, IPA moves researchers toward a deeper understanding that is context specific, and appreciates the dynamic interplay of participant and researcher in the research process. Researchers seek to ground themselves in the interview text, while observing the influence of their own interpretations on data analysis (Finlay, 2011).

Hermeneutic Circle. Perhaps the most salient concept in hermeneutic theory is the hermeneutic circle (Smith et al., 2009). Most writers adopt this model, however, it has not been attributed to any one scholar. This concept concerns the dynamic relationship between each part of a whole and the whole itself, on multiple levels. To understand a part, the hermeneutic circle attests that one must look to the whole. Conversely, to understand the whole, one must look to each part. While this belief can be discounted for its circular logic, it captures the non-linear thinking integral to effective interpretation. For example, the meaning of a word is made clear by the context of the sentence in which it is embedded. At the same time, the meaning of this sentence is dependent upon the cumulative meanings of each word it comprises.

For IPA researchers, the hermeneutic circle is a helpful conceptualization of the iterative process of analysis. It serves as a reminder that meaning can be accessed at different, interrelated levels of a text, and that each provides a new perspective on how the parts and the whole are related.

Idiography. In contrast to the nomothetic approach dominant in psychology research, the idiographic approach focuses on the particular, involving detailed analysis of individual cases (Finlay, 2011). Rather than seeking to generalize at a population level, or uncover universal laws

of human behaviour, ideography is predominantly concerned with the particular. IPA focuses on experiential phenomena, as they occur for particular people in particular contexts. This commitment is evident in IPA's use of small, specifically situated samples. IPA's bottom-up approach requires micro-level analyses of participants' contextual experiences, before tentatively considering themes across cases. Taken together, these accounts move IPA researchers towards a more general understanding of the phenomenon in question.

Smith et al. (2009) remind researchers not to conflate idiography's focus on the particular, with a focus on the individual. Phenomenology views human experience as fundamentally complex, blending unique embodied, and perspectival aspects, with a worldly and relational nature; human beings are conceptualized as less discrete than the word, 'individual', typically connotes. Given that the experience of Dasein is an "in-relation-to" phenomenon, each person's unique perspective of the construct under study contributes to its greater understanding, without such experiences being the exclusive property of each individual.

Strengths and limitations. It is important to be aware of both the strengths and limitations of conducting research with the IPA methodology. IPA is a relatively new research approach that is still being extended, amended, and reviewed, which has led researchers to adopt different variations of IPA procedure (Larkin, Watts, & Clifton, 2006). While researchers suggest that IPA may be useful in counselling research, it has not yet been widely used in the field. This means that IPA's actual effectiveness as a methodology that contributes to the development of valid and reliable counselling psychology knowledge remains uncertain. In a review of the literature employing IPA, Brocki and Wearden (2006) concluded that the quality and depth of findings may be limited by the lack of consistent guidance regarding ways in which

researchers should interact with participants and interpret interview data. Finlay (2011) also cautions that IPA requires researchers to analyze data in considerable depth, which requires significant time and commitment from the researcher.

While Willig (2008) criticizes IPA for its inability to identify causal relationships between phenomena, others argue that this is not its goal, citing IPA's success in enhancing understanding of critical processes through sustained interpretive engagement (Finlay, 2009). Eatough and Smith (2006) elaborate, affirming that interpretive revision facilitates more abstract sense-making and exposes broader theoretical and cultural issues. The rich narratives elicited through IPA are thought to powerfully illuminate phenomena including embodiment, emotion, cognition, language, culture, and contextual factors (Finlay, 2009). Finlay also attests that when a systematic approach to IPA is employed (i.e., those outlined in Eatough & Smith, 2006, and Smith & Osborn, 2008), researchers increase the rigour and robustness of results contributed to the evidence base in psychology research.

Participants

Rather than relying on a large participant sample to provide a nomothetic understanding of a phenomenon, IPA's idiographic emphasis fosters a deeper understanding of individual participants' unique experiences (Clarke, 2009). Based on Smith and Osborn's (2008) recommendation, the current study involved four participants, enabling the depth of analysis integral to IPA. Inclusion criteria included: (a) having received a clinical diagnosis of T1D between the ages of 18 and 30, (b) having maintained said diagnosis until the time of participation, (c) having received a T1D diagnosis within the last 3 years, (d) the ability to read, write, and converse with ease in English, and (e) the desire to share personal experiences of T1D.

Exclusion criteria included: (a) having received a T1D diagnosis more than 3 years ago, despite being diagnosed in the designated time span, (b) currently experiencing suicidality, psychosis, substance dependence, or marked cognitive impairment, and (c) having a limited command of the English language.

Such research candidates have been asked not to participate, based on classic findings that suggest people are unable to retrieve 50% of critical details of salient events after five years (Bradburn, Rips, & Shevell, 1987). Psychological comorbidities needing immediate attention would not receive adequate support from this study and people with such diagnoses were asked not to participate. Lastly, participants were required to be fluent in English, due to the demanding nature of the unstructured interviews required.

After obtaining consent, recruitment flyers advertising the study (see Appendix A) were posted at Vancouver hospitals' diabetes clinics (see Appendix B). In addition, the directors of "Young and T1", a volunteer driven organization connecting people with T1D between the ages of 18 and 30 in British Columbia, agreed to notify members of the study via social media (see Appendix C). Snowball sampling was also employed. Engaging in this research may have benefited participants personally, as it allowed them to voice their unique stories, advocating for themselves and their peers.

Data Collection

After identifying an appropriate sample, 60-minute interviews were scheduled at the participants' convenience. Each began with a discussion of informed consent, and participants were made aware of the study's purpose, and interview procedures. The researcher discussed the study's commitment to confidentiality, in addition to its limitations. For example, participants'

were identified by numbers rather than names in all written reports, and interview recordings were be stored in password protected digital files. Participants were informed of their rights to refuse participation, or to withdraw from the study at any time, and for any reason. After participants signed the consent form (see Appendix D), a demographic questionnaire (see Appendix E) was administered to each participant, requesting information including age, ethnicity, symptoms present prior to diagnosis, and date of diagnosis.

The unstructured interviews that followed were audio taped, and the researcher recorded field notes. Open-ended questions were asked, and minimal encouragers were used to promote elaboration, without leading participant responses. The researcher followed an interview protocol (see Appendix F), but interviews were predominantly client led. At the end of each interview, a list of local counselling service providers was given to each participant (see Appendix G)

Data Analysis

Data analysis for this study observed the procedures outlined in the IPA literature (Eatough & Smith, 2006; Smith & Osborn, 2008; Shinebourne & Smith, 2008). As an inductive approach, IPA presents flexible guidelines designed for researchers to adapt to a variety of subjects (Smith & Dunworth, 2003; Smith, Jarman, & Osborn, 1999; Smith & Osborn, 2008). The methodology assumes that the researcher endeavours to learn something about each participant's psychological world. This was achieved by examining beliefs and constructs expressed or implied in each interview, and by considering whether the accounts themselves represent parts of the respondents' identities (Smith, 2003). The model allowed themes to emerge from the personal accounts of participants instead of shaping them to fit a predetermined theory, permitting me, the researcher, to consider original possibilities (Clarke 2009). IPA required me

to adopt both emic and etic perspectives in my interpretation (Reid, Flowers, & Larkin, 2005). The former ensured that I placed participants' narratives at the centre of the analysis, while the latter encouraged me to make meaning of the data by introducing interpretations that were grounded by participants' verbatim quotes (Reid et al., 2005). Essentially, my aim was to understand content, as well as the complexity of meanings, in individual narratives and across cases. Finlay (2008) adds that reflexivity is indispensable to IPA, asserting that researchers must maintain awareness of the ways in which their pre-understandings and personal experiences affect data analysis.

Stages of analysis.

Stage 1: Identifying themes in the initial case. After transcribing each participant interview, analysis began with a detailed look at the first interview transcript. Consistent with IPA's ideographic approach, the I began at the level of the individual before gradually building up to more general themes and categorizations (Smith, Harré, & Van Langenhove, 1995). First, I read and reread the initial case transcript several times. Repeated readings are thought to immerse the researcher in each participant's world, making the researcher more responsive to each narrative, and subsequent interpretations more valid (Shinebourne & Smith, 2008). Using the left-hand margin, I began to make annotations, taking note of anything that appeared significant. At this initial stage of analysis, Smith and Olson (2008) maintain that there are no rules about what must or must not be commented on, and that there is no need to divide the text into meaning units (Smith & Osborn, 2008). My notes summarized or paraphrased the participants' messages, and reported contradictions or amplifications expressed. They also

included preliminary interpretations and associations that came to my mind, as well as thoughts on participants' choices of language.

Once an entire transcript had been processed in this way, I returned to the start, and used the right-hand margin to record emerging theme titles (Smith & Osborn, 2008). These are concise phrases that convey the essence of what was found in the verbatim text, while moving the participant's response to a slightly higher level of abstraction, and allowing for theoretical connections within and across cases. Because I was using an IPA framework, it was imperative that a coherent thread linking the theme title to the original text be apparent. While the entire transcript is considered data, IPA has no requirement that every participant response generate a theme. It is thought that passages evoking more disparate themes is an indication of their relative richness.

Stage 2: Connecting themes in the initial case. The second stage of data analysis elaborated on my initial notes, introducing abstractions and psychological concepts to uncover more specific themes (Eatough & Smith, 2006). At this level of analysis, I infused interpretations with metaphors, typically initiated by participants. It was necessary to move between inductive and deductive positions, conceptualizing participants' accounts with sensitivity, and without jeopardizing the connection between my interpretations and the participants' own words. Ultimately, I engaged in an iterative process designed to refine understandings and interpretations, until a degree of closure was achieved (Eatough & Smith, 2006; Shinebourne & Smith, 2008).

Emergent themes were listed as analysis continued, in the order that they appear in the transcript (Smith & Osborn, 2008). As I looked for connection between themes and attempted to

make sense of these connections, concepts began to cluster together and some emerged as superordinate themes. To visualize, and better understand the task at hand, Smith (2004) encourages researchers to "imagine a magnet with some of the themes pulling others in and helping to make sense of them" (p. 71). He suggests that the researcher continually cycle through earlier stages of analysis to ensure that the integrity of participants' actual experiences is preserved, and a directory of quotes related to chosen themes is compiled.

Eventually, a table was created to convey higher-order themes, and their subthemes. I named the categories therein, with titles that described the conceptual nature of the themes they comprised. Excerpts from the data were chosen to accompany each theme, substantiating the categorical decisions I made, and grounding my analysis in participants' original narratives (Shinebourne & Smith, 2008). At this point, it was appropriate to eliminate certain themes that lacked rich supporting evidence and were tertiary to the emerging structure (Smith & Osborn, 2008).

Interpretations in this stage of analysis drew upon different theoretical ideas as ways of enhancing one's understanding of the original text. When introducing theories, it was important to take direction from the data, as it is not appropriate for researchers to further personal agendas by incorporating pet theories (Shinebourne & Smith, 2008). These authors state that a researcher's success in executing this stage of analysis can be verified when another person is able to follow the analytic path from the raw data set, to the finished table.

Stage 3: Continuing analysis with subsequent cases. For samples of ten or fewer, Smith and Osborn (2008) recommend setting aside the table of themes created from the initial case, as opposed to using it to orient analysis of additional cases. They suggest following the steps

delineated in stages 1 and 2 for each individual transcript, before comparing thematic structures across cases. Only then were convergences and divergences identified within the full data set, and a final table of superordinate themes was constructed. As new superordinate themes emerged, I reviewed earlier transcripts, and included any supporting evidence that I had previously overlooked. Enduring themes were not chosen simply based on their prevalence within transcripts, as the richness of individual passages and how they elucidated other aspects of the text was important to consider.

Stage 4: Writing up findings. IPA is not complete without a narrative account from the researcher, of the dynamic interplay between participants' original expressions of experience, and the researcher's own interpretive process (Shinebourne & Smith, 2008). This stage expands analysis, translating final themes into a statement elaborating on the meanings inherent in participants' experiences (Smith & Osborn, 2008). This involves moving between participants' descriptions and different levels of researcher interpretation, clearly distinguishing the two at all times. My conclusions are substantiated by direct quotes from the original transcripts, allowing readers to assess the fit between participant accounts, and my understanding of them (Elliott, Fischer, & Rennie, 1999). This required me to retain the nuance of participants' accounts, while situating them in a framework that illuminates the phenomenon under investigation. The subsequent discussion links the emergent thematic analysis to existing theory and literature (Smith & Osborn, 2008).

Cautions when using IPA. IPA cannot be treated like a typical, qualitative thematic analysis, divorced from phenomenological and hermeneutic theory. This reductionist approach would fail to convey the subtleties and meaning inherent in participants' experiences of shared

phenomenon. Finlay (2011) cautions that it is tempting for researchers to become overly reliant on participants' original statements, accepting them as reality. Consistent with the hermeneutic nature of the IPA methodology, I allowed the data to inspire appropriate interpretations, while appreciating that these results represent a range of other possible meanings. I was careful not to focus exclusively on cognitions and sense-making, as the holistic exploration of participants' embodied lived experiences is a hallmark of IPA research.

Trustworthiness and rigour. Smith (1996) provides suggestions for enhancing the trustworthiness and rigour of qualitative research. First, he stresses the importance of internal coherence, urging researchers to assess whether the arguments presented in their papers are truly supported by the data. Secondly, Smith advises that the evidence presented include enough data from participants' original discourses, so that consumers of research can evaluate the accuracy of researchers' interpretations. To increase the likelihood that these conditions were met, an additional researcher without vested interests in the current study independently audited the data analysis and resultant interpretations. As advised by Murray and Harrison (2004), we discussed any discrepancies until a consensus was reached.

CHAPTER 4: Results

This chapter presents findings from participant interviews, and analyzes their importance. Consistent with the phenomenological perspective that people are intimately connected to the objects, relationships, and environments that comprise their lives, we begin with demographic and contextual descriptions of this study's participants. Next, participants' reflections on their initial diagnoses are shared. As the chapter proceeds, I elaborate on the key themes and shared meanings that emerged during data analysis. These results begin to answer the research question: What are the lived experiences of people diagnosed with type 1 diabetes in emerging adulthood?

Participant Demographics

Four adults were interviewed for approximately 60 minutes each. They also answered a brief demographic questionnaire, listing their ages, genders, ethnic backgrounds, and education levels. Participants included two males and two females, ranging in age from 21-29. Each had been diagnosed 3 weeks to 3 years before being interviewed and have sustained these diagnoses. All participants described having some post-secondary education, and two hold bachelor's degrees. All participants are Canadian, two of whom reported British heritage, one who described Vietnamese descent, and one who did not specify further. At the time of their interviews, all participants resided in the Greater Vancouver regional district.

Participants' Reflections on Diagnosis

While some participants were more symptomatic than others prior to their T1D diagnoses, all four reported receiving the news during particularly stressful seasons of life. Prior to diagnosis, participants' resources were largely directed towards normative life tasks for their age group: launching careers, pursuing education, building romantic relationships, and forging their

unique paths in life. Each participant's T1D diagnosis story included a series of critical events that demanded his or her immediate attention, and ultimately altered the course of life.

Participant #1 (P1) reflected on his experience, saying:

You know what, like, diabetes is the cherry on top. I was going through a lot of stress workwise. I just recently got a new job. I was also trying to lose weight. I made it a point to like, make some real big life changes: change my diet, change my workout habits, all of that. So I was losing weight, and I was losing a lot.

At first, he felt excited about these results and assumed that the changes to his nutrition and increased activity level were responsible for the symptoms he experienced (i.e., frequent urination, headaches, mood swings, and pallor). However, as these symptoms grew more alarming P1 soon began looking for another explanation. "I went out on a couple trips with my friends to the bar, had a couple drinks, and I was blacking out early. And I had no memory."

A temporary loss of consciousness was also a precursor to Participant #3 (P3)'s diagnosis, disrupting her busy lifestyle. "When I was first diagnosed, I was working two jobs and going to school," she recalls. She knew something was awry after what began as a routine vaccination, "I went to the pharmacy, I got the vaccine, and then I passed out. Paramedics came. It was super embarrassing." Later that week, blood tests revealed critical glucose levels, and she was urged to report to the nearest hospital immediately.

I was sitting in the bathtub and my phone rang, it was like seven or eight in the evening. It was the lab, and they're like, "You need to get to the hospital right away. What's the closest hospital to you? Your blood sugar levels are critical. You need to go right now."

Prior to his diagnosis, Participant #4 (P4) reported, "I was feeling in great health." Aside from his insatiable thirst, that is. "I noticed I was just drinking more water, and didn't think too much of it at the time. I just figured, 'Drinking more water. You're supposed to do that anyways, so great. I guess I'm being more healthy.'" While on a trip together, P4 casually mentioned his

new daily intake to a friend who worked as a doctor. “He asked me how much and I told him, ‘Nine litres.’” After the trip, P4’s girlfriend insisted he see a doctor, so he decided to visit a walk-in clinic prior to a hike they’d planned for the same day. P4 describes what transpired at the clinic:

I go to the doctor and tell him what’s going on. He measures my blood glucose with the little machine and the prickly thing that I’ve learned all about. So, he measures it and it was 36 [mmol/L, the standard unit used to calculate sugar concentration in the blood], which meant nothing to me at the time. He’s like, ‘Oh! You need to go to the hospital!’ I’m like, ‘Well, I’m going on a hike, so like, next week?’ He’s like, ‘No, you need to go to the hospital.’ So, I’m like, ‘Okay. So after I finish the hike, this evening?’ He’s like, ‘No. Right now. Drive to the hospital right now.’ I’m like, ‘Oh. I don’t really want to do that.’

What P4 did not understand at the time, was that his blood sugar reading was approximately six to eight times higher than the target range for a healthy adult, putting him at risk of diabetic ketoacidosis and other grave complications.

P4 decided to go to the hospital as instructed, expecting to wait hours to be treated. “The triage nurse reads the papers [sent by the doctor] and she’s like, ‘Don’t go to the waiting room. You’re gonna sit in this special chair over here, and we’re gonna get you in real fast.’ Then it started to hit me. Like, ‘Maybe it’s good that I didn’t go on that hike.’”

For Participant #2 (P2), the diagnosis was made after a blood panel revealed elevated glucose levels. “It’s the timing in general with the rest of my life. I don’t know if it was all related or not, but it’s just a lot of bad things happened in a very short period of time.”

She hadn’t suffered many symptoms prior to her diagnosis, but a bout of hypoglycaemia as she adjusted to insulin therapy led to an unfortunate accident:

I was asleep one afternoon and I woke up and I was hypoglycaemic. For some reason I stood up on my bed, half asleep, hypoglycaemic, and fell off and broke my arm. It was a really bad break. I had to get it reset twice, and then it didn’t work. I had to get surgery,

and then I had to move [out of my apartment] the day after my surgery. Yeah, it was really bad.

A T1D diagnosis is not always straightforward for doctors and patients alike. While P1's symptoms concerned him, he was pleased with the way his diagnosis was handled by the medical community once he sought help. He explains that others don't always fare as well, "Based on my interactions with all these other diabetics that I've met, probably dozens, they didn't get the same treatment as me, they didn't get the same information."

Like others diagnosed in emerging adulthood, P2 and P3 recall medical professionals being perplexed by their cases due to their ages and body types. "We don't really understand why you would have it based on your family history," doctors told P2. P3 recalls her family doctor recommending a glucose tolerance test, the first indication that diabetes was even a possibility, "I remember sitting in her office and she was like, 'It's just to rule out diabetes. I mean, it doesn't run in your family. You know, it's just to rule it out.'" Even when the out-of-range results had P3 admitted to hospital, the emergency room doctor was surprised to see a young, slender woman as his patient. "You're not what I was expecting!" she recalls him saying. "This is really strange. You don't fit the profile." This led P3 to be misdiagnosed with type 2 diabetes and prescribed a course of treatment T1D is not responsive to. Doctors eventually realized that her presentation was consistent with T1D and P3 joined others in implementing the numerous changes required to avoid harmful health consequences.

P4's diagnosis was similarly ambiguous, "Right off the bat they didn't know if I was type 1 or type 2. They gave me some Metformin and another one, which is type 2 medicine, primarily, and then the doctor also gave me insulin, cause that's more for a type 1. So, I had both for a while." At the hospital, P4 was initially told that he'd be staying two to three days in which he'd

have appointments with a nutritionist, endocrinologist, and other diabetes experts. However, the insulin administered upon arrival brought his blood glucose down quickly and he was soon discharged. “Four hours later, they gave me a prescription for a glucose metre and some pills, and I'm gone,” he explains. “The only real information I got was stuff I had to do right then, ‘Take these pills and measure your blood twice a day. Read the instruction manual. Okay bye, go home.’ That's kind of all I really got.”

P4 did his best to begin managing his diabetes with the little knowledge he had:

It was kind of confusing. I have this diagnosis and this equipment, and no one was even like, ‘Here’s, how you take your blood sugar.’ It was kind of like, ‘Read the manual when you buy the thing.’ So, I go to the pharmacy and I buy the thing, get the pills, and get home and start reading the instruction manual. I've got to do all this stuff, a lot of new stuff very quickly, and not a lot of information being shared. I kind of felt in the dark for a long time. I still do in a lot of ways. Yeah, I was just planning on having a beautiful day on the mountain. Would've been great, but so much for that.

While coping with the shock of an unexpected diagnosis, participants began to face the challenges and changes necessary to manage their autoimmune disorders on a daily basis.

Key Themes & Shared Meanings

As participants’ interview transcripts were analyzed, key themes and shared meanings emerged. Each of the following themes is expanded upon below: (a) impact on daily life, particularly medical management and changes to diet and exercise; (b) interpersonal relationships, including support systems and challenges in close relationships; (c) impact of T1D on career, focusing on challenges and new opportunities, (d) feelings and emotions related to T1D; (e) one’s quest for acceptance; (f) uncertainty about the future; (g) identity; (h) resiliency; and (i) finding meaning and purpose. These themes represent significant, and often shared, elements of participants’ experiences living with T1D.

Impact on Daily Life. When people are diagnosed with T1D, the ways in which they lived their lives are altered indefinitely. Beyond hospitalization and ambulatory care, one must quickly develop the tools for self-management of his or her condition. This involves adapting to life-sustaining therapies as well as one's changing body, nutritional requirements, and activity needs. Contact with medical care generally increases; participants describe visits to various members of their medical teams, which include endocrinologists, family doctors, pharmacists, nurse educators, nutritionists, naturopaths, counsellors, and medical laboratory professionals.

Medical Management. Hospitals typically offer diabetes education classes and individual appointments to teach newly diagnosed men and women to understand and manage T1D. Attendees learn to check their blood sugar levels using a glucose metre and to monitor fluctuations. Many learn to estimate the number of carbohydrates they consume at each meal in order to calculate the insulin dosage required. Insulin is injected manually with disposable needles or administered by an electronic pump, connected to the skin with thin tubing and worn outside the body. P3 recalls her first experience administering insulin, as a nurse educator demonstrated:

So, I'm sitting in front of her and she's showing me how to give myself insulin, how to inject it. I held the pen [device for injecting insulin] for like ten minutes and I kept going to jab myself in the stomach with it, but I just couldn't do it. And then she looks at me and she's like, 'Here, here.' She's about to poke it into herself and I'm like, "No, no, no. You don't need to do that!" And, so yeah, then I did it.

People are often instructed to keep records of their blood sugar readings, food intake, exercise expenditure, and physiological symptoms. This can help an endocrinologist determine the individual's particular insulin needs. Three participants described using a basal-bolus regimen when they were initially diagnosed, which involves taking two types of insulin: a long-

acting basal, and a rapid-acting bolus. A basal rate is the amount of insulin one needs to function throughout the day, before food is taken into account. Whereas bolus insulin is the dose taken with meals, allowing the body to use food for cellular energy, rather than leaving sugar to accumulate in one's blood and wreak harmful consequences. Determining the balance of insulin required, and dosing it accurately can be a process of trial and error with negative effects on daily life.

All participants report more episodes of hypoglycaemia during their initial adjustment periods, "one or two lows [hypoglycaemic episodes] a night," P1 recalls. Such an episode led to P2's aforementioned accident, and their frequency eventually led P3 to pursue a new mode of treatment. Her body metabolized insulin more rapidly than anticipated. "I was using it up really fast, so I was getting a lot of lows," P3 recalls. Her sensitivity to insulin meant that the typical, one unit increment in insulin dosing was not precise enough to meet her body's needs. For example, taking one unit with food was not enough to stabilize her blood sugar, but two units would soon cause her to sweat and shake as her glucose level dropped too low. "My endocrinologist suggested that I get a pump, because I can adjust the basal," allowing P3 to dose insulin in smaller increments, with increased precision.

Given new medications and regimens to follow, most participants described manipulating their treatment plans at least temporarily. P4 was candid about the changes he'd made in an attempt to manage side effects. Despite the potential risks of discontinuing medications without medical supervision, unpleasant physical symptoms led P4 to experiment with eliminating his insulin or his pills at different times. After cutting carbs out of his diet, P4 discovered that he could minimize his insulin needs:

With the insulin, I started going down by two units every day, and I had zero the other day. I took myself off the insulin, and I'm just on the pills. But, the other day I decided I'd rather do insulin than the pills. They make my stomach upset. I threw up at work one time, so that sucks. So, two nights ago, I should have talked to my doctor first but whatever, I took myself off the pills and now I'm just back on insulin. That's a little more manageable I think. Maybe I'll get scolded by the doctor next week, but whatever. It's my life, I'm going to do it my way.

Additional medical considerations are sometimes revealed, as T1D is often comorbid with other autoimmune disorders. This compounds the factors people must manage or monitor. P3 explains:

They have to check my thyroid, my kidney function, my heart enzymes, and for celiac. Six months after I was diagnosed [with T1D], I tested positive for the TTG antibodies for celiac. I had to get a gastroscopy. That ended up being fine, but I still have the positive TTG, so that, I have to monitor. And now I might also have colitis. Which they think might be related because it's autoimmune. So, there's that.

Lastly, participants' maintenance routines include seeing their endocrinologists every three or six months, receiving foot examinations for evidence of diabetic neuropathy, and conducting blood work every three months.

Diet & Exercise. Managing T1D requires individuals to pay close attention to their diets and exercise expenditure, making adjustments that encourage blood sugar stabilization. This can mean different things to different people, depending upon how their bodies respond to food and physical exertion. For instance, P3 exercises less than she did prior to diagnosis since hypoglycaemic episodes pose a problem:

I started trying to workout again and like, I'll go to a class and then I have to leave 15 minutes after because I've done everything that I was supposed to, but my blood sugar drops and I'm shaking, and I'm sweating.

Conversely, P1 has increased the frequency and intensity of his workouts. “I worked out, maybe 3 to 4 hours a week [prior to diagnosis]. Now I’m diligently working out 5 to 10 hours a week, which is a big investment of time.”

Since discovering he has T1D, P1 has put concerted effort into overhauling his diet and exercise habits, as well as developing creative strategies to keep his blood sugar in check. “I call them ‘lifestyle changes,’” he says. He began systematically reducing the amount of carbohydrates he consumes from approx. 150g per day, to 100g per day the following week, to 75g the week after that, “and then a couple days later, I was like, ‘You know what? I’m just gonna drop carbs, pretty much all together.’” P1 makes it a point to eat his meals in a particular order, “fibre first, protein second, and my carbs last”. This technique, coupled with his active lifestyle, help keep his insulin requirements particularly low. “That way I don't need to take any insulin, or very little, as long as I control the carbs that I eat.” A great deal of intention and planning go into preparing and packing meals and snacks for the day, “If I don't eat every three hours, I get really grumpy and angry.” P1 has also begun a strict regimen of vitamins recommended by a naturopath. “I’m religious with my supplements,” he explains, and credits them for a lot of the physical improvements he now enjoys.

P1 has developed a variety of compensatory strategies that he uses to manage his blood sugar when he wants to indulge in more carbohydrates than usual. “One would be Metamucil. You can abuse it too much, but I try to keep Metamucil as a sort of a back pocket thing. Let’s say, I want to have a cookie. I’ll have a scoop of Metamucil, or I eat it in warm water with the cookie, and then I don't need to use insulin.” The added fibre prevents his blood sugar from spiking. “Another little trick is ab workouts,” P1 adds:

[They] are probably the best workout because you burn off carbs the fastest. I test my blood, say I'm at 11 [mmol/L], well, I'm going to do 50 crunches, wait a few minutes, and then I'm going to test it again. Now I'm down to 8.5[mmol/L], alright I'm going to do another 50 crunches."

On social nights, he sometimes capitalizes on the glucose-lowering effects of alcohol, "I'll even just have some wine first, just to lower the blood sugar and then compensate with carbs. I know it's not good for your kidneys, but at least your blood sugar's managed, right? [laughs]" P1 uses the tricks in his repertoire in an effort to accommodate his body's new needs, while maintaining pleasurable aspects of his pre-diagnosis lifestyle.

P4 was keen to reduce fluctuations in his blood sugar. "I realized that eating meals with carbs, stuff was just going to go up and down all the time," he reported. "I'm not really interested in weighing things or measuring too much, so I just stop eating carbs all together." P4 resumed a nutrition plan he'd followed several years prior, when he, "first decided to get healthy and stop being fat and lazy." He describes the Paleo diet he adopted, "Short version, it's basically meat and vegetables. No carbs, no sugar." He reported losing 30lbs in 12 weeks the last time he'd followed a Paleo diet and was hopeful that it would help him with this new health challenge. Reflecting on whether the shift has been difficult or not, P4 shared this vignette:

Two times I've been out to restaurants with friends. They're eating burgers or whatever else, entrées and pasta. I'm there with my chicken salad. It's good, but man, I wouldn't mind having a burger or two. But [eating Paleo] is the only way that I found to keep the [blood glucose] levels stable. So, I'm going to stick with it.

Participants' relationships with food and activity shifted, as they experimented with what worked for their bodies and their lives. As they learned to navigate the new responsibilities of daily life and to troubleshoot unexpected challenges, interactions with significant others were also influenced.

Interpersonal Relationships. While some experiences were deemed positive and others negative, all participants described the integral roles other people play in their adjustment to life with T1D. Participants listed relationships with family, friends, medical professionals, peer groups, counsellors and government agencies as influenced by their T1D diagnoses. Each interpersonal encounter described, references a source of support, or an opportunity for scrutiny and misunderstanding.

Support System.

Family & Friends. P1's friends and family were instrumental in procuring a diagnosis and supporting his adjustment. In fact, it was two friends that initially posed the idea of getting tested for diabetes; one friend is a type 1 diabetic himself, and the other is a pharmacist. P1 recalls his family members' reactions when they learned of his diagnosis, "My three older sisters, wow, were they ever so super strong. One of my sisters is a doctor, one's a nurse, and one's a genome scientist, so, I've got a lot of support there. They never skipped a beat."

He followed his sisters' advice to get multiple medical opinions and to begin researching as much as he could. His mom was concerned at first and unsure of how to cook to accommodate her son's new dietary restrictions. She has since learned to adjust her cooking to include more vegetables and fewer starchy carbohydrates. P1 describes an unexpected outcome of his diagnosis, "the way [mom] eats now, she's benefiting from my diabetes. She sees, 'Wow, you lost a lot of weight with all this diet control. I can do the same.' So, even my mom lost 15 pounds."

P4 experienced similar support from his mother after sharing the news of his diagnosis:

When I told her, I didn't do it over the phone or in a text or anything so she could see my face and know that I was okay. That I wasn't worried, so she wouldn't have to be worried

either. So, I took her out for lunch and I told her. She asked a few questions about how it works and what changes and all that. Then we just had lunch and it was fairly normal, a normal conversation. A couple days later she came over and cleaned my house for me. That was her way of contributing and caring, which was great. I should get diabetes more often, 'cause that was awesome [*laughs*].

Since then, P4's mother has brought over home-cooked meals for his freezer:

I know how to cook for myself, but it's kind of nice not to. It's not about the food. I could get my own food and cook it, and I'll be fine, but yeah, it's definitely nice to be able to receive those gestures and know that she's caring about me.

P2 and P3 experienced a global sense of support from family and friends. "They were pretty good about it. They were really good about it actually," P3 says of her family. "It was just kinda like nothing was different and they were supportive." However, both participants felt less connected to other people adjusting to similar circumstances than P1. P2 told to the interviewer:

I don't feel like I relate to people who have type 1 diabetes. I also don't know anybody with type 1 diabetes, except probably now you to be honest. I don't know of anybody. I heard someone on the bus talk about it the other day [*laughs*]. I was like, 'Oh, that person has type 1 too.'

P3 shares this impression, "It's definitely isolating," she says.

Medical Care. Three participants had positive feedback about their medical teams, and particularly appreciated the support offered early on. P2 shares, "I really like my endocrinologist, she's awesome. With things, she's efficient and I really like that. I had a good experience with that and I felt good about the interactions I had with everyone at [the hospital]. Staff at the hospital's diabetes clinic was described as "so kind and really helpful." P3 echoed this sentiment, "My diabetes centre and my endocrinologist were really great."

Yet some participants took note as the amount of support they received decreased with time. P2 illustrates this point:

It's kind of weird afterwards [post-diagnosis], 'cause I got so much help at the beginning...but then you only see your doctor once every six months. So then I'm just kind of doing it my own way [*laughs*]. There's not a whole lot of [people] watching over you, so it's really on you to be watching yourself. No one is going to be like, holding your hand through it. It's a strange transition from having a lot of help, having a lot of people talk about you even. And then now, people basically just forget that I have it.

The drama of initial diagnosis and the attention it attracts creates a stark contrast to the relatively infrequent medical follow-up individuals receive as they stabilize. This means that some people must adjust to a myriad of changes without much continued guidance.

P4 reflected on the support he wished he'd gotten during his initial diagnosis:

I didn't know everything, the exact levels of blood sugar, and how the pancreas works and all that. That I didn't need. But it would have been really nice if someone kinda sat down, for someone to be like, "Hey, you're going to have to eat a little bit different. You're gonna have to watch your food. You may have to give yourself shots all the time. There's gonna be pills. You've got to be careful with your levels. You can still run, you can still go on hikes. You can still go to work. And other than that you're still going to feel pretty much the same as before. You've just got a couple extra things to do." And even just that short conversation would've been nice because then I'd know what I'm up against, I'd know what's coming.

Peer Support. Only one participant discussed intentionally connecting with peers dealing with relatable circumstances. The positive benefits he received make this a notable topic, despite being uncommon among the participants interviewed. "I decided to volunteer with [a major Canadian organization that provides research funding and advocacy for T1D]," P1 shares. While helping at an event, he was introduced to the founder of a peer-support network and was soon asked to take on a leadership role within the organization, "and ever since then, my life's changed." Volunteering in the diabetes community has connected P1 with peers and mentees going through similar transitions. He describes the effects of interacting with other type 1 diabetics, "It's been awesome. I met a whole new group of friends through being a diabetic, and it's funny that you get to relate instantaneously with a stranger, it's like an unspoken connection."

Counselling. P1 was actually referred to a counsellor as a direct result of his diagnosis, while others described the benefits they received from including private counsellors in their care. A doctor connected P1 with a Canadian Diabetes Association outpatient program, where he visited nurses specializing in diabetes once a week for two months after his diagnosis. “They coached me, but not only that, they referred me to a counsellor. All of it was free. I didn't have to pay a single cent for it. So, obviously I took advantage of that opportunity.” In counselling, he had the opportunity to work through negative feelings he'd been experiencing since before his diagnosis, as well as to discuss the recent changes to his life. P1 experienced tangible results quite quickly. “I took six sessions and got everything back on track. Now, I'm completely fine, no more depression or anything,” he attests. Others addressed diabetes with their counsellors more indirectly, still acknowledging positive effects. P2 reports:

I talk to a counsellor every once and a while. I actually didn't even mention it [the T1D diagnosis] to her the first couple times, like, I just forgot. And then last time I went to see her, I really talked about it, and it was interesting talking to her about it.

P2 went on to describe the insights she gained from their conversations, and how her counsellor helped her to see herself and her situation from new perspectives.

Government Subsidies. Three participants described receiving some support from government agencies in the form of financial coverage for certain medical supplies and procedures. P1 reports, “Finance-wise it was really stressful because I wasn't making the money I am today. So, I found out that our government would give us [people with T1D] some type of tax break.” Motivated by her eligibility for federal funding, P3's decided to try an insulin pump as an alternative to multiple daily injections. “Since I was still under 25, I was still covered by Pharmacare.” Despite P3's initial reluctance, her endocrinologist urged her to take advantage of

the coverage, as it would no longer be offered the following year. “She was like, ‘You know, you’ve got to hop on that!’” Without insurance subsidies, an insulin pump costs approximately \$8000, and requires supplies to run that cost hundreds of dollars each month. There is accumulating evidence from observational studies, randomized controlled trials, and meta-analyses that suggests insulin pump therapy improves blood sugar regulation, reduces the frequency of severe hypoglycaemia, and lowers the risk of cardiovascular mortality when compared to multiple daily injections (Misso, Egberts, Page, O'Connor, & Shaw, 2010; Pickup, Kidd, Burmiston, & Yemane, 2006; Pickup, Mattock, & Kerry, 2002; Pickup & Sutton, 2008; Steineck et al., 2015; Yeh, H., et al., 2012). Nevertheless, it is not a viable option for many people with T1D due to the expense of the device and associated supplies. Currently, there is no government coverage for people over 25 years of age, regardless of the age at which they were diagnosed.

Challenges in Close Relationships.

Scrutiny & Misunderstanding. All participants reported receiving increased scrutiny and misunderstanding from others following their diagnoses. Participants were hesitant to say anything that would show their loved ones in a negative light as they appreciated the support of family and friends. P3 explained, “They want to help, but they don’t understand. You don’t really understand unless you’re going through it, and it’s kind of frustrating.” For example:

My mom will ask, ‘How’s your blood sugar?’ and if I say it’s high or it’s low, ‘Well, why is it high?’ or, ‘Why is it low?’ Or if it’s low and I’m just kinda eating the whole kitchen, she’s like, ‘What are you doing?!’ Like, ‘You’re bingeing! The doctor said you’re only supposed to have 15g of carbs!’ And I’m like, ‘Try having a blood sugar of 2.7 [mmol/L] and still dropping. I’m gonna eat everything!’

P4 appreciated his girlfriend’s concern, while also feeling irritated about being monitored:

She was pretty worried about me for a while. She was always texting, asking what my levels were. She wanted me to text her every time I measured [my blood glucose] and let her know what they were and all that. Nice to be cared about. If I'm being honest, [I was] a little annoyed to be checked in on all the time and have to report back, a little bit. I'm not doing that as much anymore.

P2 feels frustrated when family members' judge her food choices:

I'll be eating a chocolate once. Like, I never eat sweet food, not just because of diabetes. And they'll be like, 'Uh, is that really what you're supposed to be eating?' and I'm like, 'Shut up! It's a piece of chocolate!'

P2 also commented on the experience of others not being able to relate to her:

Just like me before diabetes, they don't really know, and don't fully understand. As much as you try to explain it to people, not everything can be absorbed if it's not affecting them immediately.

For example, people are not always understanding of P2's need to find food quickly when her blood sugar is dropping, "I'm not just saying that I'm hungry because I'm being annoying. I do need to eat something. Like, seriously." She negotiates a fine balance between making her needs and concerns known to others, and trying to keep T1D in the background of her life, "I'm always feeling conscious of whether I'm bringing it up too much, or like, I struggle with making sure I do mention it."

P1 appreciates his friends' concern, while feeling annoyed by their questions at times.

"Now they're all asking me, 'Hey, should you eat that? Should you be drinking that much? Are you sure you can go out? Are you sure you can handle it?'"

He also describes more offensive encounters: "Because I'm so controlled with my diabetes, I've even had people accuse me of lying about having diabetes." P2 shares her frustration about when a friend said she talks about diabetes a lot. She's actually intentional about not discussing the subject much, "It's so annoying, because I mean, it's part of my life."

P3 shares, “I’ve had friends that didn’t understand how my mood would change when my blood sugar was low or high.” They would be confused by the changes in energy and emotion that accompanied P3’s rapidly fluctuating blood sugars. “They think because your A1C [measure of average blood sugar reading over 3 months] is fine and your blood sugar is okay, they think that you’re okay. They don’t understand that you’re managing. It’s a constant thing.” The relentless nature of T1D and the actions necessary to manage its effects can be taxing on individuals as well as their significant others.

Dating Issues. Romantic relationships were not immune to the challenges of T1D, and interestingly, three participants describe their T1D diagnosis as implicated in their subsequent break-ups. P3 shares:

I had been dating a guy for two years and we broke up because I was still always tired and always sick. He didn’t understand. So that was really shitty. Really shitty. He kind of thought that it was going to go away, like it was going to get better and was like, ‘Your sugars are normal, you’re fine.’ And, that’s just not really the way that it works.

P2 was also disappointed by her boyfriend’s reaction. “He didn’t understand it. He was like, ‘It’s not a big deal.’” She explains that he had the flu the same week she began taking insulin and that his demands felt unreasonable:

I was like, ‘I can’t take care of you. I need to deal with my own shit right now,’ and we got into a huge, explosive fight. To this day, I think like, not that because I have diabetes he broke up with me, but because I was going through this thing, it made me look bad or something, and he just didn’t want to put up with it. Part of me has always thought, if I didn’t get diagnosed with diabetes, he probably wouldn’t have broken up with me. It was pretty shitty.

P1 describes being overwhelmed as he tried to maintain a relationship on top of the other demands on his time and attention: “I had a girlfriend right when I got diagnosed and um, I just couldn’t handle it. The diabetes, depression, the girlfriend, so I had to let go of her.”

P4 and his girlfriend have sustained their relationship and he describes her as caring and supportive. Nevertheless, P4's diagnosis caused some misunderstanding and tension early on. He explains:

In the first week or two, when it was a little rougher, I was more quiet and less energetic than normal. [My girlfriend] was over one evening and she could tell. There was other stuff on my mind too, but diabetes was certainly one of them. She's like, "Hey, want to talk about it? What's going on?" And, I kind of realized like, I didn't really, you know? It's not that I was trying to shut her out, but I didn't want these things on my mind and diabetes to be like, the focus of my life. I just wanted to do whatever, and just kind of be normal. Yeah, we had to talk about that because I think she took it that I was kind of shutting her out, and not bringing her into what was going on, but that wasn't my intention.

P4 reflected on desire for the time they shared to be focused on more positive things, and to maintain the sense of normalcy he craved:

I just wanted to have a normal evening you know, and just do something fun, make some popcorn or...I guess not make popcorn anymore [a Paleo diet does not include grains]. You know, just have a normal evening like we did the week before, or two weeks before, and not have this diabetes, this stuff, consume my waking hours and always be the focus of what I'm doing. I just kind of wanted to leave it alone and just be normal, and do normal things. So that's what we did and it was good.

For P1, re-entering the dating scene as a newly diagnosed diabetic came with its own complications. He shares:

I've been in a couple dating situations where I've met girls and I tell them that I'm a diabetic and they tell me, 'Well that's weird, I've never met anybody sick, nobody sick in my family,' and then we never really talk. It's pretty shallow. It's really shallow, so probably wasn't meant to be anyways. I feel like some people out there, they really look down on you.

P3 puts the awkwardness of dating with a life-sustaining medical device into perspective, "Trying to date now is really weird. I mean, if I want to have sex I have to unplug myself. And then I have scars and holes all over my hips. It's really hard."

Impact of T1D on Career. Participants shared a variety of ways in which adjusting to life with T1D influences their career options, performance, and choices. Participants experienced some changes as negative, while others have led to new career opportunities that inspire optimism.

Challenges. Career challenges described include intrusive physical symptoms, health insurance coverage, as well as others' misconceptions and perceptions.

Firstly, hypoglycaemia poses a challenge on the job, as its symptoms include anxiety, confusion, sweating, tremors, dizziness, and blurred vision, which impair one's ability to attend the task at hand. When blood sugar drops below the optimal level for efficient bodily function, one must consume glucose to compensate. At work, this may mean stepping away from one's job to eat and monitor symptoms until blood sugar is balanced and normal functioning returns.

P3 works in a medical setting where colleagues tend to be more informed and receptive than they may be in other contexts, "So, work's pretty good about it," she explains. She goes on to discuss how she deals with hypoglycaemia on the job:

I'm constantly getting low [hypoglycaemic], having to stop working for a sec. If I can, [I'll] kind of like run back, grab something to eat, and like, I have no problem saying, 'Sorry, but I have to sit down, or I'm pretty useless right now.' Like, 'I just need 15 minutes'.

Still, she admits, "I push through it a lot," continuing to work despite her body's panicked state. Unfortunately, even when blood sugar stabilizes some symptoms may persist. "Sometimes after a low, I'll feel like shit for two hours. Having to push through that is exhausting."

P4 shares the desire to avoid hypoglycaemia at work, though he prefers to keep his diagnosis private from colleagues at this time. "I haven't told my coworkers yet about the diabetes," he reports. Consequently, he is discrete when using the necessary supplies:

If I'm going to measure my blood glucose, I just go out to the parking lot and sit in my truck for now, and do it there. At some point, I'll transition to bringing it in, but I don't know, I just don't want too many things to change right away.

P2 discusses a practical financial concern that influences her career-related decision-making. She had planned to quit her job to take time for travel, but hesitated before committing to the decision as she considered the toll it would take. "What about coverage?" she questioned, "I'm not going to be covered for a bunch of expensive things that I have to get for diabetes. That's kind of scary... giving up a medical plan." P2 explains. "Had I not had diabetes, I probably would have quit and gone travelling sooner."

In addition, P2 began to question whether her diagnosis could really preclude her from certain occupations. "I read this thing [online], '10 Celebrities You Never Knew Had Diabetes,'" which pointed out that the individuals were actually still famous. "Then I was like, 'Well, I didn't think [diabetes] would affect your life so much that you couldn't be an actor or an athlete.'" And I'm like, "Wait, does it?"

New Opportunities. P1 explains that his T1D diagnosis has led to unexpected new opportunities as a speaker and mentor for young people confronting chronic illnesses. In addition to working full-time, P1 now invests significant time and effort volunteering in the diabetes community and beyond. "Luckily for me, I consider it a hobby," he shares. "I've joined a [large peer-support] group where they've made me the Director of Outreach and Mentorship. So now I oversee a group of 170 people," he explains. "I've been a part of some workshops through the BC Children's [Hospital] where we talk to youth [and] I picked up an opportunity to be a Big Brother," he continues. "So, it's compelled me." He reflects on his changing priorities since being diagnosed 3 years prior:

It's brand-new, it's all brand-new stuff. Within the last three years, it was at first really just getting my diabetes in control and now I'm moving into a mentoring role. I don't know, maybe I can make a career out of it, who knows. These are all things that go through my mind as life goes on."

Feelings & Emotions Related to T1D. As participants adjusted to new routines and responsibilities, their feelings and emotions varied in tone and intensity between participants as well as across time. P3 recalls her feelings leading up to a pivotal moment when the impacts of her diagnosis came into focus. When lab technicians discovered her irregular test results and advised her to report to the nearest hospital, she describes being in a daze, "Just kind of like, 'La-dee-dah,' not really sure what's going on. She adds, "We stopped for coffee on the way." At the hospital nurses quickly began administering fluids intravenously. P3 says, "I was in a super daze. Like, I had no idea why they were checking me all the time. I still hadn't clued in." The next morning:

I was sitting with the doctor- my parents had just left to go and grab me some stuff. I'm sitting there with her and I'm asking what the [blood sugar] reading is, even though I had no idea what it was or what it meant. I'm like, 'Oh, it's high.' Like, 'I don't know why it keeps doing that.' And she looked at me kind of like I was stupid, and she's like, "It's 'cause you have diabetes." And then it just kind of all, I don't know, it just crashed down. I was like, 'What?! Oh my God!' I started to cry and I got kind of pissed off and the doctor was like, 'Why are you crying?' And I was like, "Why do you think I'm crying?!" "It just kind of hit me that my whole life was about to change. Or it had changed, and I hadn't even realized it.

Feeling shocked, she quickly focused on implementing practical changes and monitoring physical outcomes. P3 felt confused and emotionally blunted as she took immediate action to improve and protect her health, "I still wasn't sure how I felt about everything. I was just kind of like, running through the motions, doing what I had to do."

Later, as P3 began using an insulin pump and adapting to the nuances of this new delivery mechanism, she became more disappointed and discouraged:

It was a bit of an ordeal. It wasn't really what I had expected and the saleswoman said that there were features that there weren't, or maybe I misunderstood. I don't know, but, I was not happy about it. I cried a couple of times because like, who wants to wear a device? So, so yeah, then I got [the insulin pump], and at first it was really hard getting used to.

She restricted her food intake after diagnosis, in an attempt to control her blood sugars, and the accompanying anxiety, "I hardly ate carbs because I was afraid. I wasn't eating anything."

As participants described the life-altering impacts of T1D and their effects on daily life, some grieved the loss of old, perhaps more carefree ways of living. P2 spoke to the difficulty of what relying on external insulin sources now means, and how it influences her life and future, "Well, one other thing was really hard for me. It's kind of hard for me to grapple with. It might make me cry," she elaborates:

I started insulin for the first time, and that was really hard for me. I'd say that was the hardest part. And so, when I started insulin, I was like, 'Whoa.' I felt like, 'My life is gonna change a lot'. I kind of got worked up about it. I didn't know what it was going to be like. It was really stressful for me.

Reflecting on the events of the year she was diagnosed, P2 said, "I did have a really difficult 2015, just in general. I just started insulin and I was really depressed, not clinically depressed, just like, really sad about it."

She had reached overwhelm during a hospital stay for one of the surgeries required to repair the arm she broke in a hypoglycaemia-induced accident:

The nurse who was doing my surgery, she had to write down a note being like, 'emotionally unstable,' or something like that. I was like, 'You don't have to write that!' And she's like, 'Um, I'm just going to write it, just in case.'

She explains how the onslaught of new challenges threatened to overwhelmed her resources at the time:

I had to move in on my own and I've broken bones before, so luckily I've dealt with that before, but I've never lived on my own, period. And I definitely haven't lived on my own

with a broken arm. So, it was like, really different. You know, you can't cook, you can't clean, I couldn't unpack, there were a lot of things.

P2's ability to follow her prescribed insulin regimen, and get adequate nutrition began to decline. "And then I stopped taking my insulin. I couldn't even like, do the insulin." She explained the difficulty she had trying to screw a new, sterile needle tip on the injection device each time she ate anything with carbohydrate, with only one viable arm. "And then I still didn't feel like eating and you know, I couldn't cook, so I just stopped taking my insulin basically."

Considering the changes she's experienced since this especially difficult time, P2 reflects:

I think it ebbs and flows. Like, in the summer, it was really good, and then I had a really hard time in the fall, and then now I feel I'm really good again. I mean, I think it's just gonna be like an up and down [thing]. And grappling, grappling with everything."

Three participants described feeling annoyed and inconvenienced by the amount of time and effort they now expend on daily self-management of T1D. "It's the inconvenience factor that affects me most, because obviously, you know, taking insulin is annoying," P2 stated in a matter-of-fact tone. She listed the extra supplies she had to purchase before her upcoming trip to Asia, including a special bag designed to keep insulin refrigerated while travelling in hot climates.

"It's just things that last time I went travelling, I would never think of doing, or having. It's just this whole other layer, and it's a fat layer, of things to think about," she says, alluding to the new considerations and anxieties she now has as a result of her diagnosis. "It's added an inconvenience. It's making decisions more complicated."

P3 agrees, "It's a *lot* of work. And it's really frustrating," she says of the new behaviours and routines she now implements daily, some several times a day. For instance, she generally monitors her blood glucose when she wakes up, before meals and snacks, before, during, and after she exercises, before she goes to sleep, and sometimes multiple times in between. "I'm

constantly checking,” she says. The results supplied by the glucose metre are based on small samples of blood that P3 obtains by pricking her fingertips. This means that each time she wants to gather information about her blood sugar level, she must draw blood using a small disposable needle, cocked and released by a spring-loaded device.

She is vigilant to avoid hypoglycemia and the way its symptoms make her feel. “They’re just, oh my God, so horrible,” she discloses. P3 hoped that things would feel better after she began taking insulin, yet the adjustment was challenging, “I still wasn’t feeling good. I was feeling worse, because now I’m getting these highs and these lows, and I’m anxious. It was just too much.” The anxiety she experiences around T1D is pervasive, “It’s always at the front of my mind,” she reports.

P3 reflected on the new challenges and limitations she experiences, mourning the loss of enjoyment she used to get from things like eating and working out:

I actually get really frustrated and I cry, because not being able to do things that you want to do, it really sucks, especially after I could do those things for so long. And now it’s just kind of like, you know, people don’t understand.

Similar to other participants, P4 recalls quickly focusing on solutions rather than attending his emotions shortly after diagnosis:

I didn't really ever take the time to process what was happening, it was just kind of, go to work, check my blood because the doctor said to, put it in a spreadsheet, and take these pills, and I was just kind of going through the motions there.

He was later able to acknowledge the anxiety and how the lack of information he had troubled him:

You know, there's all these worries I wasn't even worrying about at the time. There's so many things it could have been. I kinda started going through all the bad things that people have, diseases people have, all these symptoms. And I don't know, I don't know very much about diabetes. It's just kind of like the lack of knowledge was almost overwhelming [sic].

P4 also expressed frustration around his new diet and its restrictions:

“It was a bit weird switching back into Paleo, almost a frustrating thing. The last time I did it, I was eating Paleo because I chose to eat Paleo. At any time, if I want to go eat a cake, I can eat a cake. It doesn't help with losing weight, but nothing really bad happened. But this time eating Paleo, it's because I have to eat Paleo. It's not really something I'm choosing. A little bit of a frustration I guess. It was kind of, I'd rather be doing it because I'm choosing it, not because I have to.

Lastly, he acknowledged the pressure he feels to manage his blood sugar effectively, and the stress of watching his blood sugar drop to dangerous lows:

Every once in a while it just reminds me I have this like, serious thing, I have to take care of constantly. And every time I measure my glucose it's kind of weird because this number that I have, it keeps going down all the time and it's kind of like- I'm sorry if I'm being more morbid or anything, but it's almost a countdown to my death, and then I have to reload every once in a while [with glucose].

While P1 shared other participants' frustrations about the day-to-day maintenance of T1D, he had a different take on his experiences. P1 credited his T1D diagnosis as the catalyst that led him out of the depression that had plagued him prior, “I used to be depressed. The diabetes played a big factor in that because it was like, my last straw, I hit rock bottom.” He described the ups and downs in his mood during this time:

Depression, you know, is a funny thing because you don't feel depressed all the time, but when you do, you're really in this deep dark cave. So, some days I'd be super positive and super motivated, but in the back of my brain I would always think to myself, ‘You know, if I think too positive, something bad is going to happen.

P1's initial diabetes care providers referred him to a counsellor and he believed the relationship was beneficial, “Diabetes gave me the opportunity to talk to somebody and sort myself out from A-to-Z.”

Quest for Acceptance. Three participants discussed their struggles to accept life with T1D as their new reality. P2 reflects on her difficulty assimilating this new information, “I think to

this day, I don't fully believe it. I definitely struggle to accept that I have it," P2 admits. Her self-awareness regarding this lack of acceptance stemmed from an eye-opening conversation she had with her therapist, a woman P2 says, "knows me quite well." P2 had neglected to mention her T1D diagnosis in previous sessions, and remembers her therapist's response when she eventually opened up about it, "Honestly, it doesn't sound like you've accepted it at all." Initially, P2 was shocked to hear this, but now agrees there is some truth to her counsellor's statement. "I'm like, 'Oh...I think that's true. Like, I haven't fully come to terms with it.'" She'd prefer not to think about the morbid consequences of T1D, but feared this isn't a sustainable option, "If I don't think about it now, then it's going to get bad and I don't know if it's going to be irreversibly bad. It's scary if I'm like, "Will it only sink in when [my health] gets really bad?"

P2 explained how she doesn't want T1D to direct her life, yet the persistent worry and anxiety around T1D does influence her thoughts:

My blood sugar hasn't been too high, so I'm kind of like, "Well, then do I really even need to worry about it?" That's kind of worrisome. I'm like, 'I'm fine.' So I don't worry about it too much, and then I'm worried that something horrible is going to happen and I'm just going to be like, 'Shit! I should have paid more attention to it!' It's like a fine line between worrying and not worrying. I don't want to worry about it too much. I'm like, [T1D is] not going to change my life', and then, I need to worry about it a little bit so that I don't have bad complications.

P3 described her diagnosis as "so surreal," and explains that subsequent adjustment has "just been really hard." She recalls a conversation she had with her father at the hospital, following her diagnosis. Her father's perspective contributed to the sense of acceptance she is developing:

Dad was like, 'You know, it could be a lot worse.' Like, 'It's something that's manageable.'" He's like, 'You know, there's people that have it way worse than you. I mean, you're lucky enough that they caught it and there's nothing's really wrong with you. It's just like, something you have to do.' I was still kinda like, 'Why is this happening to

me?” But I just kinda was like, ‘Okay, I’ve gotta do what I’ve gotta do. I’d rather not die, or lose a limb, or whatever. [sic]’

P2 shared the same motivation driving her to do the things she doesn’t want to do that are necessary for T1D management. “I’m not going to lose a limb or have anything like that happen,” she affirms.

P1 described more positive feelings towards having T1D, while experiencing his own disbelief at times. “I keep asking the doctor, you know, ‘Is my pancreas actually dead?’” He is optimistic that the change won’t be permanent. “I’ve heard of cases where people have reversed it. Who knows? I don’t know; I hope that I’m one of those guys.”

P4 is slowly revealing the news of his diagnosis to family and friends, but has some hesitation in doing so. He does not want his diabetes status to become an identifying detail, and is concerned about being treated differently:

I don't know that that would happen, people are pretty respectful and accommodating. Probably it's just in my head. It won't be that big a deal when I do tell my coworkers, but just for myself, I kinda want most things to stay normal and kind of slowly have things change- just not all of a sudden, in one big go. I wouldn't feel like posting on Facebook, “Hey everybody! I’ve got diabetes now!” I don’t want a pity party because that’s just depressing for everybody. It takes energy away from everybody. I’m happy to listen to advice and learn how to do this better, but other than that, I’ll figure it out and keep on going.

Each participant shared nuanced patterns of emotion as they endeavour to understand and accept the reality of their conditions and work to mitigate damage. Yet, all expressed attitudes consistent with P3’s view that life with T1D is one “long learning process.”

Uncertainty About the Future. Since being diagnosed with T1D, participants’ visions of the future have shifted, as they try to anticipate the long-term implications of diabetes. The diagnosis provokes people to consider their own mortality, and to cope with the feelings that

arise. The worst part, P2 reports, is “knowing the fact that it’s going to get worse. It’s not going to get better, unless I’m cured, but generally speaking, it only gets worse with time. So you’re like, ‘That’s kind of a shitty prognosis.’”

Without a clear prognosis for each T1D case, uncertainty about the future weighed on participants’ minds. Three participants reported being in the ‘honeymoon period’ of T1D. This term refers to the period of time when one’s pancreas continues to produce a small amount of insulin, maintaining some blood sugar control and reducing the need for subcutaneous insulin. P2 hoped doctors could confirm when her pancreas would stop producing insulin completely, but they informed her of its unpredictability, “It could be a couple of months, it could be tomorrow, it could be five years from now,” she says.

P4 highlighted the difficulty of not having a point of reference, not knowing what to expect in the weeks and years to come:

Even as I'm reading about stuff, I don't know if that's all of it. You know, I read, ‘You've got to do this. You've got to do that,’ but I don't know when I’m done. Even now, I don't know if I've come across everything that's going to change about my life. I think I have, but there's no definitive list. If someone who had diabetes could've been there and been like, ‘Hey, this is what my life’s like now.’ That would've been super to have that idea of what was coming.

Participants’ ideas of what to expect as they grow older are largely based on information shared by their medical teams, anecdotal reports from peers or the media, and personal research.” P2 shared how others’ experiences have coloured her own:

I’ve heard other people’s stories of how they were diagnosed with type 1 and they only figured it out when it’s past the honeymoon period. You lose like, 30lbs in a few weeks, and then, and you know, something really bad happens and you have to go to the hospital.

She explained that there is a lot yet to learn, though she’d rather avoid thinking about these things due to the stress they evoke:

I don't really understand what ketones are, I don't. There's things that doctors warn me about, and I don't really know what [they] mean. Like I know that ketones in your urine is bad, but I'm like, 'Do I know what that is?' Or, 'How am I going to tell if I have that?' There's still just things that I don't really know. And I don't really want to think about [sic].

Much of what P4 knows about diabetes he had recently learned from articles and online research. His surprising findings led P4 to begin considering his own mortality.

I was reading some articles about diabetes and I came across this one. They were talking about some guy and how he got an award for living to be 80. I was like, 'Why are we giving this guy an award for just living to be eighty? He must've discovered something or done something to earn this award.' No, there's actually a foundation that gives people with diabetes awards just for living to different ages. 'Why, why do they do that? That's weird! Who cares how old someone gets? That's not an accomplishment.' So, I was reading more and that's the night I learned that the average life expectancy for type 1 diabetics is 11 years shorter, for men at least. So, that was kind of a lot. Not that I'm necessarily losing 11 years off my life, but statistically that's the average, which is a little depressing.

After P4's first episode of hypoglycaemia, he began to read into the topic, "I was reading about it more and it ends up that if your blood sugar gets too low, you can like, die." He shared his surprise at the morose information he uncovered:

I was reading that 5% of diabetics die from hypoglycaemia, so I guess just making a mistake with food and all that. So it kind of just made the seriousness of this more real. Up until then, I had been to hospitals before, I'd been to doctors before, but it was never gonna be like, 'You could die tomorrow if you make a mistake or do something wrong.' It was more like, "You need to take the pill, or have this surgery and then you'll be fine." It was never really like death was on the table. So that was kind of scary. Pretty serious business, it's not just like. 'Take these pills and do this meter.' It's more like, 'No. If you screw up, you're actually done.'

Since then, P4 is pacing himself, "one piece of bad news a day is as much as I let myself read."

Having T1D also made P1 more acutely aware of his mortality, and he hopes that the condition is not implicated in his demise.

I've seen some friends die because they didn't look left before crossing the street, or they were in the wrong place at the wrong time. You know, there's a million other things that

can kill me other than my diabetes. So it doesn't have to be the diabetes that kills me. I really believe that too, I don't think the diabetes is going to be the reason why I die. Maybe partially, but, who knows. You can't think like that anyway. Anybody can die at any moment. You gotta live life for right now, make sure that you make the most of it [sic].

Identity. Participants alluded to an invisible line, distinguishing the person he or she was before T1D, and the person he or she is now. Each searched for meaning as they integrated new information about their health with their pre-existing self-concepts and senses of identity. Participants spoke of how T1D shifted their priorities and altered the ways in which they experience themselves in the world.

For P1, T1D motivated him to dramatically change his lifestyle, and he is very satisfied with the results, "I completely rebuilt myself from the ground up. I'm completely brand-new." He maintains tight control of his blood sugars for which his diligent approach to exercise and nutrition is largely responsible. His T1D is so well managed that his medical team considers him something of an anomaly, "they're like, 'Yeah, you're a type one diabetic, and you're just weird.'" Discovering he had T1D compelled P1 to transform his lifestyle. Since adopting a rigorous exercise routine and changing his approach to food and nutrition, P1's body has transformed. He reports having more confidence and feeling happier, "without the discipline that I've just recently built, none of this would have happened."

P1 reflected on how T1D impacts him, "It's not running my life. But on the same breath, it does." He went on to explain the sacrifice and commitment required to enjoy the benefits of stable blood sugars:

Because as awesome as that sounds, it takes a lot of working out, stress control, sleep- diet control is the biggest thing. Like, I only eat 15 to 30 grams of carbs a day- in the morning, and then the rest of my diet is protein, fat, fibre, very little dairy. I'm religious with my supplements B12, D, calcium, [etc.]. I had to do my research, put my time in, to kind of

control everything. But, I'm fortunate enough that I had the brain and the discipline to do it all.

The threat of T1D complications motivated P1 to prioritize his needs, and to devote significant time and energy to following a meticulous routine. The stress of a chronic disease diagnosis and the demanding learning curve it brings had effects on his relationships. He and his girlfriend had broken up shortly after finding out he had T1D. He shared how his outlook on dating and relationships has changed:

I feel like a lot of my time is devoted to working out or controlling my stress. I have to be particularly selfish to just take care of my health, so whoever is next in my life has to understand that. A lot of my life is devoted to me now- making sure that I live a long and healthy life. But also, I want to be there for that person and hope they can understand.

He looked to the future with optimism, saying, "Relationships, regardless of if they're friends or [girlfriends], they come and go. You got to just keep moving, keep thinking positive, otherwise you just destroy yourself early."

Since being diagnosed with T1D, P1's focus and interests have shifted dramatically. He is enjoying the results of his lifestyle changes and expects that his new eating habits, exercise regimen will be long-lasting:

I always tell my friends, you know, 'Even if I was cured of diabetes, now I'm just going to be a workout machine because it's great.' I feel great all around. It's way better. But, you know, people without diabetes, I guess they feel like they're a little bit more indestructible, and they don't take it seriously.

P3's sense of identity was also affected by her T1D diagnosis. This becomes more apparent when she goes on dates, or meets new people in general. She is conscious of how much attention her health status should merit, "I've honestly just started dating, a little bit. But it's kind of hard for me because it's like, you don't know when to bring it up, or when to say something."

She usually wears an insulin pump, but it's bulkiness and her desire not to have to explain it to people sometimes motivate her to leave the device at home: "If I'm going on a first date, I don't wear it. So, then I go to the bathroom after I've ordered my food if we're having dinner, and I'll give myself the insulin." It is not that she is ashamed of having T1D, she just doesn't want it to take centre stage in early conversations with each new person she shares a meal with:

It's not so much that I don't want people to know, because honestly it doesn't bother me, that part. It's just, especially if I'm getting to know somebody, I don't want [T1D] to be the number one thing. 'Cause that's not, you know, the only thing. I know for a certain time, like, that's all anybody wants to talk about, just that's not the only thing I want to talk about. I don't want that to be the main thing that people see when they look at me.

P4 was also adamant that diabetes will not define him, and is cautious about who he shares his health status with. "I didn't want it to be a big thing. I'm quite introverted, so I don't really like a lot of attention. I also don't want to be like, 'the guy with diabetes'. I just want to be [me]."

P4 does not want a diagnostic label to change how others perceive him, or limit the options he sees for himself in life:

A lot of it is that I don't want stuff to change, because diabetes is a negative thing. I don't want to walk into this negative identity and have that become any part of me. I don't want any of the negative parts of it. I don't want to be any more sad than I was before, or more tired, or anything negative. I don't want to absorb that if I can avoid it. So, I'm just kind of hesitant. I'm almost trying to keep the diabetes at arm's length. I just want to keep being me, living my life, and not have too much more stuff change.

P4 does his best to keep diabetes in the background of his life:

I don't want it to be a massive thing. I don't want to change everything. I want to be as normal as possible and talking about it all the time feels less normal. That's kind of the biggest thing I didn't want, you know, for everything to change. Like I said before, I don't want to be 'the diabetes guy'. I just want to keep being [me], and maybe do a couple things different. I don't want it to be the big thing about me. I don't want that to be my identity.

For P2, the concept of being a person with T1D still seems foreign. “Like, even [my friend] contacting me about this study, I was like, ‘That feels weird,’” she says. She provided an example of how distant the concept feels with a vignette about going to a new doctor:

I go to the doctor. They’re like, ‘Okay, you’re totally healthy,’ and I’m like, ‘Yep.’ 20 minutes into a conversation I was like, ‘Wait, I have diabetes. I’m type one.’ And they’re like, ‘What?’ Like, ‘that’s a main thing to mention, like at the beginning, when I’m talking to you, and I asked you.’ I totally forgot, to be honest. Like, ‘I would have told you if I remembered.’ So, it’s one of those things- It’s integrating it into your life [sic].

P2 reflected on that integration, acknowledging that adjustment is a process:

I think it’s all about the fine line between things. Re-learning certain things about the world, or about yourself, or about other people, your relationships with them. When you get diagnosed you’re like, ‘Oh. Okay...’ I don’t have health concerns, I never did. And so learning what having a health condition- a life-long disease, it’s weird.

While participants grappled with what their T1D diagnoses mean to them, and how this autoimmune condition impacts their personalities, they also discovered new resources and personal strengths.

Resiliency. Participants shared stories that exemplified their resiliency, as they managed their T1D diagnoses and adjusted to new realities. Reflecting on their experiences led some participants to recognize new capacities in themselves. P2 reports, “I’m more optimistic, and I’m adjusting well.” P3 looks back on what she’s learned in the two years since she was diagnosed, “I’m a lot more adaptable than I thought that I was. Yeah, that’s probably been the biggest thing”

Participants expressed gratitude and demonstrated hope, practicing positive thinking, and finding new ways to cope. Remarkably, all participants mentioned how lucky they were to have been diagnosed with T1D and not some disease they feared more, or made downward comparisons to people they perceived as worse off. P2 shares the way she viewed her situation:

I'm like, kind of lucky because everyone has a thing. You know, everyone suffers from something. And so, I'm like, 'This isn't that bad,' like, 'It's manageable, it's you know, moderately common, and it was diagnosed quickly and easily. So overall, I mean, it's a pretty lucky thing to have if you're going to have a thing. And by thing, I mean something wrong with your health.

P1 choose a similar outlook:

The way I took it, I was like, 'Wow, thank God it is only type one diabetes and nothing else. You've got to look on the bright side because there's some diseases and autoimmune deficiencies out there that completely eat away at your life. Whereas, diabetes, it's manageable [sic].

P1 perceived T1D as preferable and less debilitating than cancer or HIV. P4 shared similar sentiments about his diagnosis, "You know, it's better than cancer, or Huntington's, or something like that."

Participants shared the ways in which they motivate themselves to do what's necessary to care for their T1D. "I try to stay positive about it," P3 explains. She is among the three participants who specifically mentioned positive thinking as a strategy they use to cope. P3 shares an example of her efforts to stay optimistic:

I have to get blood work every three months, which was hard at first because I didn't like the needles. I had this one vein- I don't like it. For some reason, I just can't stand the way that that feels. So I had this one vein I'd always make them use, and I just upgraded myself to start using regular needles instead of the tiny little butterflies [smaller needles used on people with shallow veins or who are prone to anxiety]. So it's like, I don't know, trying to find little things to change.

P4 looked to the future with hope, thanks to new advancements in technology and discoveries in diabetes research:

I'm reading more about technology and there's hope there too. There's some guy they've operated on, and they were able to insert islet cells into his pancreas somehow. Super advanced medical stuff- and he's been insulin-free for a year! He was dependent on it for 30 years before that. Lots of new technology's coming out, so I feel like after a couple years, things are looking good. There's a lot of promising stuff there.

P1 worked with his counsellor to improve his outlook and mood. Soon, his thoughts began to change. “I would say my real positive thinking really started to pick up steam right after my third counselling session,” he reports. P1 has developed a positive thinking style and explains how it has benefitted his overall life, in addition to his adjustment to T1D. He describes his propensity for optimism, “I’m a positive thinking guy. So, whatever is thrown my way, I always try to see some type of opportunity for it.”

He observed other people he considered successful, and describes the mindset they inspired:

[They’re] just thinking of exactly what they want in life and sure as hell is it’s gonna happen someday or another. You may be stumbling along the way, and bad times may ensue, but as long as you just keep moving forward, and you’re just motivated, you’re going to get there. So that’s sort of been my philosophy with everything. Which led me to this [interview], which leads me to other opportunities that are coming up in the future.

P1 intentionally focuses on the silver linings his new lifestyle changes bring, rather than ruminating on the costs. For instance, he has a new outlook on exercise that keeps him motivated:

Physical activity is not the easiest thing. You don’t want to do it. You want to be lazy, and lay around, you know. So, in some way you pay for it with time, but at least with working out, you’re working on becoming a better-looking person, a healthier person anyway.

He shares other benefits of his new commitment to exercise, “I’m running a marathon now with a group of ten diabetics.” And, “it’s also given me like, less than 10% body fat.”

P4’s shared another creative approach to coping with the stress of daily diabetes management. He likens the task of keeping his blood glucose in range, to a game:

Last week my blood sugar has been a hundred percent within the safe target. It feels good to kind of accomplish something. Not that I’ve like, beaten diabetes but, I don’t know, like I’m winning a little bit. Yeah, it’s kind of like gamification by accident. You know, everyone always turns everything into a game to motivate people to do stuff these days,

and that's just kinda how diabetes is. And I don't think anyone did it on purpose, but it's sort of like an inverse high score. Keep the numbers down, or in my case I have trouble keeping the numbers up. Just managing these numbers, it's kind of like a game. It's a little personal challenge. It kind of makes it, I'm not gonna say fun, but better than it could be, you know [sic]?

Meaning & Purpose. Two participants spoke directly about their searches for meaning as they adapted to life with diabetes. Their reports were distinct, and reflect the experiences of men at different temporal points in their journeys: P4 was interviewed just three weeks after his diagnosis, while P1 had been adjusting for three years.

During his initial hospital visit, P4 began to question the actual meaning diabetes would have in his life:

I was just kind of sitting there, not really sure what's going on. It's all pretty new and I don't really know what that means to have diabetes. It's all kinda vague. Something to do with needles and blood sugar, that's all I really knew.

As P4 moved through the initial shock, a myriad of unanswered questions nagged at him:

It was very much like I had no idea. What is the total meaning of this? What does this mean for my life? What is the impact on my life? What's going to change in my life? I'm like, Am I gonna die sooner? Am I gonna be tired all the time? Am I gonna be able to keep working? Am I gonna have to stop physical stuff? You know, no longer go for runs, go to the gym? What is the impact on my life? What is really gonna change here? No one really laid it out for me, and in my mind it was almost worse than the reality. What is a diabetic person's life like? I don't know.

P4 described how his natural temperament made it even more difficult to sit with this uncertainty and lack of understanding:

I really like to know what's going on. I tend to kind of over plan things. I work as an engineer. I am always analyzing and making spreadsheets and all that, it's kind of how I live my life. So, the thing that was tough for me was, I just, I didn't really know what was going on. And there was very little that was being told to me, and that is what kind of made it tough because I didn't really know what I didn't know. I didn't know what this meant or where this was going.

With time, P4 discovered more about what it meant to be living with diabetes. He experienced a tangible loss when his doctor advised him not to participate in the adventure race P4 had made of tradition of competing in. “That was a little bit sad because it's kind of a pivotal thing I do every year,” he reports. His doctor had been working with P4 to determine an appropriate insulin dosage. “He was worried I'd end up hypoglycaemic in the trees somewhere, which is valid,” P4 explained.

The event has held significance for P4, since he first became involved four years prior. In an effort to improve his health and fitness, he'd made it a goal to complete the race. This year, P4 stayed on the sidelines, supporting the group of friends he'd planned to compete with. “You know it's kind of a bit more of a thing than that for me,” P4 admitted. He went on to elaborate:

The first [race] was kind of a marker that I achieved some level of health and fitness that I've never had before. It was a milestone for me, so I've done it again each year since then. What's interesting this year, is that I didn't run because I'm not healthy. It was kind of a sad thing because I didn't have that pivotal point where I was like, “Yep, I can still do this. I've maintained my fitness.” So, not like a huge drop, or a huge depression, but [I was] kind of a little bummed there on that one. Next year everything should be okay. Everything should be worked out. I'm going to be able to do these things again I just have to wait a little bit.

P4 was optimistic that this was a temporary setback, and that he'd be able to return to his hobbies and passions in the future. While diabetes posed a challenge, P4 was adamant that it would not dictate the course of his life.

Conversely, P1 spoke at length about the unexpected advantages his T1D diagnosis had brought. Since being diagnosed, P1 is on a new trajectory in life that is bringing with it a new sense of meaning and purpose. He is now an advocate for others and an active member of his community. He offers education and mentorship to other young people diagnosed with chronic diseases. P1 explained how, “giving back” had led him to experience deeper connections and

more life satisfaction. “Yeah, I definitely used [my diagnosis] as a blessing,” P1 reflected.

Thinking about how T1D changed the course of his life in surprising and ultimately positive ways, he reported:

It's giving me the opportunity to make a difference now, and to stand for something because before my diagnosis, I felt pretty lost in life. You know, just working, career and making money, but never really felt like my self-actualization, like it's foundation was being built. So now that I'm in this whole diabetes role, I've been a lot happier and felt driven to do something for people.

By volunteering in diabetes research and advocacy groups, P1 found opportunities to facilitate workshops for children transitioning to young adulthood who have chronic diseases, “We don't really get to talk much in these workshops, we don't teach. We just ask open-ended questions and we let the group discuss by themselves. It always comes out to be this awesome open event.” He also helps people one-on-one, and values the reciprocal benefits this creates:

I picked up an opportunity to be a big brother for a teenager. He's type one diabetic, and so I'm in the midst of mentoring him. Changing his life and in turn, it's helping me out and healing my soul.

P1 appreciated how these new opportunities allow him to pass along what he has learned in his journey, and to encourage others to thrive despite their own hardships. “I get to instill my knowledge into other people now and relate to people who may be facing bad times.” He reflected on his innate resources and how he’s made a conscious choice to find purpose and meaning in his circumstances:

I guess I’m just mentally strong in that way. You know, positive things only happen to positive-thinking people. That's just the way life works in general. Regardless of if you have [a chronic disease] or anything, you could be a beacon of light, or you could be completely useless- useless to yourself as well. It depends on how you want to take it.

Unlike during the period of depression that preceded his diagnosis, P1 now looks to the future with optimism and anticipation, “It'll be really good. Looking forward to it all.”

He ended his interview by sharing his message of hope for other people diagnosed with T1D:

Regardless of if you've been a diabetic as a kid or if you're recently diagnosed, do your research. You can always be a better person. Don't link it to diabetes. Just think of it as, 'How do I make myself a better human being today? How can I become a better person? How can I tighten up? How can I get rid of my demons? Focus on that stuff, because only good things happen when you work on yourself. And if you work on yourself first, you can take care of other people better. You can take care of yourself better. Just don't give up. And if you feel like you're ever giving up, there's other people out there who can talk to you, and you can connect with, and you gotta make it a point to connect with those people. That's what I did [sic].

CHAPTER 5: Discussion

This chapter begins with a discussion of research findings in the context of existing literature on chronic disease adjustment, and emerging adult development. Next, I present novel findings with less existing empirical support, before describing the study's limitations, and proposing directions for future research. I go on to add personal insights gleaned while conducting this study, and conclude by delineating the implications of this research on psychological theory and counselling practice.

Findings Substantiated by Existing Literature

Participants responded to the demands of T1D in creative and nuanced ways. However, the current findings suggest there are salient shared themes among these individuals, each of whom was diagnosed with T1D in emerging adulthood. A T1D diagnosis was found to have far-reaching impacts across different domains of life. Study results suggest areas of life that are salient to emerging adults confronted with T1D (i.e., career, travel, finances, social and romantic relationships, identity formation, and development of personal meaning). These topics are consistent with those which the American Diabetes Association recommends addressing for optimal T1D self-management in emerging adulthood (Chiang, Kirkman, Laffel, & Peters, 2014). These authors also recommend that ongoing education and support specific to these and other developmentally appropriate domains, be offered to people living with T1D across the life span.

Existing literature indicates that emerging adulthood is a high-risk period for psychological distress and negative health behaviours (Arnett, 2000; Helgeson et al., 2014). More opportunities for emerging adults to make risky decisions present themselves as parental supervision

decreases, and the full responsibilities of adulthood are yet to be assumed (Helgeson). This stage of development poses additional risk for individuals diagnosed with T1D, a condition often accompanied by depression or disordered eating. Psychological morbidity is linked with poor diabetes self-management, making it especially important to address psychological wellbeing adjunct to physical health (Peters & Laffel, 2011). Furthermore, qualitative research suggests that many emerging adults with diabetes may not qualify as clinically depressed, but still struggle with sub-clinical diabetes-related distress which may negatively impact glycemic control akin to full threshold disorders (Gonzalez, Fisher, & Polonsky, 2011; Esbitt, Tanenbaum, & Gonzalez, 2013).

Participants' accounts from the current research are consistent with the aforementioned literature, as all described experiencing a depressed mood, or feeling overwhelmed at some point in their adjustment to diabetes. Furthermore, all participants described temporary changes in the ways they managed their conditions, which were influenced by their emotional states at the time. For example, fear of fluctuating blood sugars and potential complications led two participants to eliminate carbohydrates from their diets almost entirely, while two others began restricting their overall food intake. Two participants also reported discontinuing insulin therapy without a doctor's consent, during particularly stressful periods.

All participants expressed gratitude for the ways in which family members helped ease their transitions to living with diabetes, while also acknowledging the challenges encountered in these relationships. Others' care and anxiety opened participants up to unwanted scrutiny and led to various misunderstandings. Common themes surfaced in the challenges observed in other close relationships. Consistent with Balfe et al.'s (2013) findings, three participants described

their efforts to comfort family members' with negative emotions related to their own diagnoses. This led some to avoid sharing personal fears and experiences in the presence of family or friends. Two participants reported feeling judged and frustrated as parents expressed concerns about their food choices, or questioned their eating behaviours. Studies have found that parents' attempts to control their children's self-management are related to negative outcomes including poor adherence to medical protocol, depressed mood, and a lowered sense of self-efficacy in managing one's T1D (Butler et al., 2007; Weissberg-Benchell et al., 2009).

Novel Findings with Less Empirical Support

In addition to the aforementioned findings, for which there is considerable empirical support, study results shed light on aspects of participants' experiences that have not been exhausted in the current literature (i.e., impact of T1D on emerging adults' romantic relationships, existential issues of mortality and identity, and resiliency). More research is needed to investigate the validity of the following findings, and recommendations for such studies can be found after the subsequent section on study limitations.

Interestingly, three participants in the current study reported that their T1D diagnoses were implicated in the dissolution of their romantic relationships at the time. Boss and Couden (2002) portray chronic illness as an, "unwelcome interloper" in a couple's relationship (p. 1354), threatening to rob each partner of who they were, or wanted to be, prior to the diagnosis. In the present study, participants' partners were described as lacking sensitivity and having unrealistic expectations during their initial periods of shock and adjustment, further disrupting participants' sense of value and self-esteem. One participant explained simply, that the demands of his relationship and the demands of diabetes became too much to cope with simultaneously. Current

literature investigates the effects of chronic illness on married couples in middle age and older adulthood (Masumi, Parris Stephens, Franks, & Rook, 2012; Robles, Slatcher, Trombello, & McGinn, 2014; Weingarten, 2013). However, it does not illuminate the impact of illness on couples in emerging adulthood that may have different priorities and goals than those of previous generations.

Other notable findings include those related to existential issues of meaning, mortality, and identity. Following their diagnoses, all participants reported questioning the meaning of diabetes, and how it would affect both present and future. Without a comprehensive understanding of the disease, and no clear prognosis described by doctors, participants felt uncertain and overwhelmed. Boss and Couden (2002) assert that, “the most stressful losses are those that are ambiguous”(p.1352). They explain that not understanding the typical progression of one’s illness can hinder positive adaptation and coping, making it more difficult to accept and manage one’s health. This can contribute to a sense of loss that the current study’s participants steered themselves against.

Emerging adulthood represents a critical stage in the formation of personal identity (Arnett, 2000) and the introduction of a chronic illness plays into this development. When one is confronted with the onslaught of new information and imperative changes that diabetes brings, they must come to terms with forces operating outside of their control. Uncertainty about the future influenced all participants’ adjustment, as they contemplated the threats of complications, amputation, and pre-mature death often associated with diabetes. Considering one’s mortality created stress that participants tried to keep at bay, and influenced the ways in which participants viewed themselves and their futures.

Participants described diabetes' influence on their sense of self in both positive and negative ways. Three participants asserted that they did not want their health status to become their identity, and did their best to prevent stigmatizing labels from limiting their options and opportunities. For example, one explained that he did not want to internalize the negative identity that can come from the idea of having a chronic, autoimmune disease. Another wished that health care providers would deliver information about the changes necessary for diabetes management in more hopeful and optimistic ways, rather than frightening patients with stories of worst case scenarios.

Two participants described efforts to conceal or downplay their T1D so that it would not take the spotlight and detract from other parts of their personalities. For example, one participant reported taking insulin in restaurant bathrooms to avoid having to discuss the particulars of diabetes on first dates. Another currently goes out to his car when he checks his blood sugar at work. As these participants renegotiated their own senses of identity and worked towards integrating the reality of their diabetes diagnoses, they did not want to change the ways in which other's perceived or behaved towards them. These participants communicated a clear message that they would prefer diabetes to remain in the background of their lives, rather than coming to define it.

An interesting dichotomy emerged between participants who sustained efforts to minimize the visibility of their illnesses and one who chose to embrace it more fully. While participants diagnosed more recently struggled to find meaning, one participant had had several years to make sense of his condition and explained how giving back had transformed his experience of having T1D. By volunteering and taking leadership in the diabetes community and beyond, he

had derived purpose, meaning, and fulfillment from these experiences. He described viewing his T1D diagnosis as something of a blessing, the catalyst in changing his life for the better.

Embracing diabetes as part of his identity led to an increased commitment to health and fitness, as well as other positive social and career opportunities. This suggests that the lived experience of T1D can be interpreted in different ways by different people, as well as across time. It also demonstrates the incredible resiliency of emerging adults in adapting to challenges and change.

Thus far, this discussion has predominantly focused on the difficulties participants' shared, but it is important to comment on the ways participants responded to the challenges of change. Participants described cycling through a range of emotions from depressed and overwhelmed to energized and purposeful, though not necessarily in a discrete or linear fashion. All participants report working to increase acceptance of their diabetes diagnosis. They demonstrated significant resilience, relying on networks of social support and employing creative coping strategies that fit their personalities and daily lives. For instance, two participants deemed conceptualizing diabetes self-management as a game, and challenged themselves to work towards incremental goals. Remarkably, all participants explained feeling grateful or lucky that they'd been diagnosed with T1D and not another disease they assumed to be worse, suggesting that downward comparisons left participants feeling more positively about their health.

Lastly, the two participants who reported seeking counselling for their psychological needs described it as beneficial, helping them to gain self insight and to make behavioural changes. While not all T1D diagnosed in emerging adulthood will identify as clinically depressed, having an ally may prove a valuable asset to self-management. Given the physical and psychological health risks emerging adults face in this phase of life, combined with the demands of normative

developmental tasks, and the stress of a chronic disease diagnosis, consulting with a counsellor as part of routine disease management may improve emerging adults' ability to self-manage and to prevent unwanted complications.

Study Limitations

The purpose of the current research was to explore emerging adults' lived experiences of T1D diagnosis and their subsequent adjustment. The goal was to gain insight into the experiences participants found meaningful, thus broadening our understanding of how people between the ages of 18 and 30 adapt to chronic disease diagnoses. I chose to use an interpretive phenomenological analysis as the study's methodology, as it was not my intention to test a hypothesis, come to a comprehensive theory, or generalize results beyond the population sampled. Due to the limited representation of T1D in the existing literature on lived experience and the dearth of research focusing on the emerging adult demographic, this study was designed to be exploratory.

The methodology elicited rich narratives that effectively illuminate phenomena including embodiment, emotion, cognition, culture, and other contextual factors (Finlay, 2009). Results point to shared meanings and understandings, which provide valuable insight into the lived psychosocial experiences of young people diagnosed with T1D at this critical time in their development. Naturally, there are some limitations to this research that warrant discussion.

Initially, I intended to conduct in-person interviews with each participant on UBC's Vancouver campus. I received positive responses from potential participants and quickly booked eight interviews. However, only one participant actually attended the in-person interview, while the rest cancelled last-minute or simply did not show up. Upon further investigation, I discovered

that participants were scattered across the Greater Vancouver regional district and beyond. With busy schedules and prior commitments to work, school, and family, potential participants found the commute to UBC a large deterrent in their limited time off. One even mentioned that with the exhaustion she feels in this early adjustment period, she was not up the drive after a demanding workweek.

The University of British Columbia Behavioural Research Ethics Board approved an amendment to this study, allowing me to conduct the remaining three interviews via telephone. The convenience of this mode of communication made potential participants more keen to engage. In changing the interview format, I noticed that the opportunity to build rapport was somewhat hindered, and nuanced behavioural cues were lost. However, the telephone format proved to be advantageous in that it seemed to encourage deeper elaboration on sensitive issues (e.g., sex, dating, and non-compliance with doctor's recommendations) that may not have been disclosed without this additional sense of anonymity.

The fact that one participant had been diagnosed just three weeks before being interviewed, while others had been adjusting for two or more years, may also have influenced results. Acute stress reactions can occur in response to traumatic events, and this study's inclusion criteria could have been narrowed to ensure the amounts of time participants had had to adjust to life with T1D were more similar.

Participation was entirely voluntary, meaning that the sample may represent people who are more comfortable sharing their experiences with others, tend to be more extroverted in nature, or feel compelled to spread the word about T1D. Following data analysis, participants were offered the opportunity assess the accuracy of the ways in which they'd been represented,

yet none chose to take advantage of this opportunity. Lastly, this study was conducted from a Western cultural standpoint in a major Canadian city and findings should be considered within this context.

Future Directions for Research

While the scope of the current research is small, it helps illuminate new directions for future investigation. Each participant expressed some confusion about what to comment on in their stories, and suggested that more directed questions could make it easier for them to organize their thoughts. As such, future research could include a more direct and detailed interview protocol, investigating emergent themes and eliciting more elaboration on each.

In addition to the phenomenological approach employed here, findings from research with a variety of qualitative and quantitative methodologies would enrich our understanding of emerging adults' psychosocial experiences of T1D. The present study focuses on those emerging adults diagnosed within the past three years, providing data on people's initial adjustment to T1D. Longitudinal research, or that which interviews people at different temporal points in their development would create a more comprehensive picture of how those diagnosed with T1D in emerging adulthood are impacted across the life span.

Additional research that helps inform screening practices for people at higher risk of developing psychological comorbidities and negative outcomes is also needed. Consistent with the literature, participants reported depressive episodes, insulin abuse and cessation, restricting their intake, and deteriorating body image as a result of having T1D. These negative coping mechanisms and mental health outcomes may be curbed with the help of trained counsellors

sensitive to clients' needs. Investigating the direct effects of counselling or particular psychosocial interventions would also be valuable.

Studies investigating potential gender differences in responses to T1D may also be useful in screening for high-risk clients. While results from the current study cannot be generalized due to the chosen methodology and small sample size, gender differences anticipated by other researchers were observed. For example, consistent with Enzlin, Mathieu, and Demyttenaere's (2002) research on gender differences in psychological adjustment to T1D, females expressed more depressive symptomatology, while men reported more active coping, and fewer avoidant behaviours.

Additional lines of inquiry inspired by this study's novel findings include, investigating the impact of T1D on emerging adults' romantic relationships, identity development, and capacities for resiliency and post-traumatic growth. Since a T1D diagnosis constitutes a crisis for many, it has the power to destabilize one's relationships and sense of identity. It is remarkable to note how some individuals are able to transform unfortunate experiences into opportunities for growth and expanded resiliency. Future research that examines positive coping and meaning making processes, may be helpful in developing interventions that promote health and healing for those who feel blindsided by their diagnosis and stuck in their adjustment process. As Stanton, Revenson, and Tennen (2007) contend, and some participants in the current research echoed, the experience of chronic disease diagnosis has the potential to inspire people to find positive meaning, to promote healthier behaviours, deepen close relationships, and to enrich one's emotional life. Studies of people who report these effects may help clinicians support others who feel more disadvantaged.

Researcher's Reflections on Conducting this Study

My desire to investigate the subjective experiences of people diagnosed with T1D during emerging adulthood arose after my own diagnosis at age 24. In this section I examine the 'insider-outsider' roles I negotiated while studying a population of which I am a member. The benefits and challenges of my position as an 'insider' are discussed, and I delineate the ways in which I was, and was not, able to relate to participants' experiences. Lastly, I share the personal meanings and metaphors derived from my own experiences adjusting to T1D and the new insights I've gleaned since sharing in others' stories.

Benefits and Challenges in Insider Research. Interpretive phenomenological analysis requires the researcher to be directly, and intimately involved in the collection of data and its subsequent analysis. While valuable in all qualitative methodologies, it is especially important to acknowledge the researcher's situation and positioning in this postmodern context (Angrosino, 2005). Consequently, I was intentional about making my identity as a researcher with T1D known to the participants interviewed. With 'insider research', as Asselin (2003) explains, the researcher shares an identity, language, and experiential base with the study participants. This provides a measure of legitimacy and credibility to the researcher, allowing him or her more access and acceptance from participants (Adler & Adler, 1987).

Padgett (2008) and Kacen and Chaitin (2006) agree on three major benefits to research conducted by insiders that were consistent with my experience: (1) easier entrance and acceptance to the community of study; (2) having existing knowledge of the subject; and (3) understanding of participants' nuanced responses. I discovered that having T1D myself facilitated participant recruitment, as I was familiar with diabetes-specific organizations which

potential participants were also aligned. Having personal insight into some experiences that participants described helped me gain trust and build rapport, as participants felt understood without having to elucidate the meaning of certain medical terms or describe the mechanisms of biological processes characteristic of T1D. Participants expressed their relief that I wasn't asking the ignorant and often irritating questions they regularly field from people to whom T1D is foreign.

My membership in the T1D population also seemed to enhance some participants' willingness to share deeper elements of their experiences that their own social networks had not been able to support them with. For example, two participants discussed their difficulties coping with hypoglycaemic episodes and the ravenous, seemingly insatiable appetite that can accompany them. They felt judged by their families and friends for these eating behaviours, whereas they reported feeling more comfortable with me, since they assumed I might have had similar episodes and a more sympathetic understanding.

While the insider position afforded me many advantages in this research, I was cognizant of how knowing my T1D status may have shaped or influenced participants' disclosures. Kanuha (2000) affirms that researchers must consider the objectivity, reflexivity, and authenticity of research in which one is similar to those under study. I noticed that some participants would abandon a topic of conversation if they weren't confident in their technical knowledge. For example, one participant was explaining what she understood of the impact ketones had had on her body, before reporting that I probably had a better understanding of the process anyways, and moving on to a new topic of conversation. This suggests that participants made certain assumptions about me based on my status as a fellow type 1 diabetic.

While an insider in some respects, I was something of an ‘outsider’ in that I took on the role of researcher rather than peer, investigating the lived experiences of different people engaged in the same phenomena. In the interests of objectivity, I was not able to relate or engage with participants as I might with a friend. This meant that when participants asked personal questions about my own experiences, I was cautious not to disclose more than that I too had been diagnosed with T1D in emerging adulthood, shifting the focus back to participants’ stories. This was somewhat difficult, as the peer inside me would have liked to comfort, and console, helping to normalize participants’ experiences by sharing some of my own. Consistent with some participants’ reports of feeling isolated and alone in their experiences, I interpreted the personal questions they posed as a desire to connect and relate with someone whom they hoped could understand what they were going through.

As I spoke with participants, I related with certain shared experiences, while differing in other respects. I anticipated individual differences within the sample population, and rather than defining myself as solely an insider or an outsider, I was aware of the dynamic movements I made between these roles. Corbin Dwyer and Buckle (2009) assert that the issues of fundamental interest in qualitative research are not simply the researcher’s status as an insider or outsider, “but an ability to be open, authentic, honest, deeply interested in the experience of one’s research participants, and committed to accurately and adequately representing their experience (p. 59).” Gould (2003) recognizes the compelling and continual tendency for humans to frame multifaceted issues as dichotomous struggles between opposite and opposing sides. Rather, Corbin Dwyer and Buckle call qualitative researchers to move beyond these insufficient

constructions, embracing the richness and complexity of the space between previously entrenched perspectives.

Ways in Which I Did and Did Not Relate to Participants' Experiences. As I analyzed the data collected, I recognized areas in which my experiences overlapped with participants I interviewed. I could relate to participants' initial shock and struggle for acceptance. For instance, the doctor who sent me for the blood tests that revealed my critically high blood sugars never actually followed up, and I only discovered that I was likely diabetic because I had subscribed to a service that lets patients view their lab results online. This contributed to the similar sense of confusion and aloneness reported by study participants dealing with medical professionals without a comprehensive understanding of T1D.

Like others I spoke to, busy with the normative tasks of emerging adulthood, my diagnosis posed a significant stress and interruption to my life plans. It came in the same month I was scheduled to travel to Europe, move out for the first time, and begin graduate studies. Similar to other participants, I initially followed doctors' advice almost robotically, hoping that my symptoms would be reversed and everything would be fine. However, in the years that ensued I eventually felt depressed, anxious, and overwhelmed, which led to unsafe periods of non-compliance with my insulin regime. While I am now much more optimistic and committed to self-care, uncertainty about the future causes some fear and distress about potential complications, and has me considering mortality at a younger age than I'd previously anticipated.

Discrepancies between my experiences and interpretations of events and those described by others also existed, particularly with the two men interviewed. Both reported working out

more intensely and frequently than they had before being diagnosed with T1D, whereas my experience has been more consistent with P3, who's blood sugar sensitivity makes it difficult to exercise vigorously without dangerous fluctuations. Both male participants described adjusting to insulin as less of a dramatic endeavour, and had few negative feelings to report, whereas my experience was characterized by frequent episode of hypoglycaemia and the loss of freedom inherent in having a medical device attached to my body at all hours of the day. I was careful not to assume that others' experiences would be the same as mine and did not want to put words in participants' mouths. I was however, curious whether gender differences in the ways chronic disease diagnosis is experienced may exist, or whether male participants may have been less comfortable sharing intimate feelings with an interviewer who also happens to be female.

The effect listening to others' lived experiences of T1D had on me is threefold: it normalized my experiences, led to social comparisons, and motivated me to move forward. Learning of participants' adjustment processes humanized the experience, and helped me to understand that we are not pancreases and will never operate as expertly and efficiently as our organs originally did. It was comforting to know that others are going through similar adjustments and that the process is one of trial and error that requires self-compassion to navigate successfully. However, I noticed self-judgement increase when I learned of others who seemed to be handling challenges more gracefully, or experiencing more ease in their adoption of new habits and ways of coping. Nevertheless, hearing participants' diverse and nuanced stories fuelled my motivation to continue improving my T1D self-management as I am moved by the lengths other young people are going to promote healthy futures for themselves, and know that success is possible.

Meanings & Metaphors. As I reflect on the somewhat esoteric meaning T1D has to me, three words come to mind: responsibility, fear, and gratitude. Like all participants interviewed, I experience T1D as a significant responsibility for which there are numerous daily obligations that I could not have fathomed prior to diagnosis. It's not that ignorance was bliss exactly, as I struggled with many confusing and debilitating symptoms. Yet, coming to know T1D was the cause of these symptoms shifted the responsibility onto me to manage them as best I could by implementing changes that transformed my experience of taken-for-granted activities such as eating, drinking, and exercising.

To partake in these necessary, daily activities now involves the aid of subcutaneous insulin and the life-sustaining pump technology that delivers it. It involves sticking myself with needles 5+ times per day, keeping records of fluctuating blood sugars, interpreting patterns, and adjusting my lifestyle to maintain or improve the results. The responsibility of having T1D means never leaving the house without a laundry list of equipment, and fast-acting sugar to consume in the event of hypoglycaemia. While I do my best to maintain the life I had before T1D, I am aware of the limitations the disease entails. No longer can I go for a spontaneous run, or enjoy cocktails with friends on a whim. There is a lot more planning required to partake in such activities, as they have unpredictable effects on my blood sugar and often lead to dangerous lows. The theme of responsibility includes the added structure my life has taken on as I attempt to keep up with medical appointments, and T1D self-management, in addition to the typical demands of school, work, and family.

The need to self-manage extends beyond medical maintenance, adding extra pressure to simple tasks. For example, having T1D makes me more motivated to keep my home organized

so that there is space to prepare healthy meals, and pack lunches. While people without T1D must also prepare meals, I experience increased psychological distress when I fall short of the expectations I set for myself, as simply buying a prepared meal means that I have less control of the ingredients, and therefore, less knowledge on which to base my insulin dosing calculations. The uncertainty of how my perceived failures will affect my future health provokes fear and apprehension about the future, a sentiment shared by all participants interviewed.

P4 conveyed the pressure experienced in each daily decision when he explained that anytime he is tempted to eat something that may spike his blood sugar, or to neglect self-care in some way, he thinks about how each such decision may decrease his lifespan. Similarly, I worry about the way my behaviours may affect not only my future health, but the lives of those that love and care about me. This can lead to feelings of guilt and shame, as I don't wish to hurt myself or my loved ones for the short-sighted purposes of my instant gratification. All participants exhibited a level of self-judgement for their perceived mistakes that normalized my experience. Conversely, listening to others' accounts intensified my shame in other ways, as I drew unhelpful social comparisons between myself and those who seemed to have coped better with certain aspects of the disease. However, I came away from this research having increased my understanding of self through the observation of others, and increased acceptance that adjustment is a process of trial and error that we are each navigating as best we can with the resources available to us in each moment.

If I were to create a metaphor describing the chapter of life prior to my T1D diagnosis, it would be: consuming time without regard for consequence. Looking back, this was a time of less maturity and responsibility in which I took for granted that life and time were laid out in front of

me. I had a vague sense of my mortality, but my expiry date seemed to lie in the distant future and was of little immediate concern. Since being diagnosed with T1D and adjusting to the new realities of life I would call this chapter: embodying acceptance, gratitude, and mindfulness. As I come to accept the body I live in, I am increasingly grateful for the experiences I'm privileged to enjoy. I can really savour the milestones, with new acceptance that almost anything can happen at any moment. When I envision the future, themes of preservation and growth come to mind. There is an ever-present urge to safeguard the health and youth I have now, as well as a desire to continue evolving, improving, and maturing in the mindfulness of life's impermanence. T1D has helped me come to know that life and time are precious gifts not to be taken for granted.

Implications for Theory and Practice

The present research contributes to a body of knowledge upon which health care professionals can develop resources and interventions, tailored to the growing number of emerging adults diagnosed with T1D. This study provides a deeper understanding of how T1D is experienced and accommodated across the lifespan, providing insight on how counsellors can be incorporated to improve continual care. The findings may interest a variety of clinicians (e.g., counselling psychologists, endocrinologists, and nurse educators) and people with diabetes alike, as competent care is a shared responsibility (Chiang et al., 2014).

Academic research conducted in the past few decades has shaped our current understanding of adjustment to chronic disease (Stanton, Revenson, and Tennen, 2007). Conceptualizations of adjustment have become more refined and nuanced, while empirical research substantiates the idea that chronic disease requires people to adapt their lives across many domains. Regardless of the particular diagnosis, chronic disease adjustment is believed to

be a continual, though not necessarily fluid, process, in which people experience both positive and negative responses over time.

Recent research has honed in on specific autoimmune diseases, and the particularly challenging domains these populations face. The bulk of such research focuses on experiences of people with cancer, while very little investigates T1D. Existing research and interventions focused on diabetes are largely tailored to children diagnosed with T1D and their parents, or adults presenting with type 2 diabetes. Emerging adults are not represented adequately, despite the rising prevalence of diagnoses among this age group, and the population's increased risk of negative outcomes and comorbidities (Chiang, Kirkman, Laffel, & Peters, 2014).

The present study contributes emerging adults' perspectives to the wider body of research on chronic disease adjustment. More specifically, it gives voice to their unique psychosocial experiences while revealing shared experiences and meanings. This exploratory research begins to bridge the gap in existing literature, identifying the salient needs and concerns unique to people diagnosed with T1D at this formative time. It also helps to convey participants' stories in their own words, adding depth and richness to our understanding of how T1D impacts people's lived experience. This more complex conceptualization of what it means to live with a chronic illness can inform development of more comprehensive theories of adjustment, and translate into improved tools for clinical assessment and intervention.

The study's IPA methodology is congruent with counselling paradigms that value the uniqueness of individuals' experiences and attributions of meaning, and seek a holistic understanding of each individual within the context of his or her environment. Due to the study's exploratory nature and concern with idiographic experiences, participants were not primed to

speaking about particular topics. Instead, they were given a general prompt to describe their experiences between the time they discovered they might have a problem and the present, including what they were thinking, feeling, and doing throughout. The themes that emerged from interview transcripts were consistent with topics other researchers expected to be significant to emerging adults diagnosed with T1D (i.e., identity formation, social and romantic relationships, career, travel, financial responsibilities, and the development of personal meaning) (Chiang, Kirkman, Laffel, & Peters, 2014), corroborating and strengthening these results.

While findings from the current study cannot be generalized due to the chosen methodology and small sample size, it does inform counselling practice in tentative ways. Reading about lived experience and immersing oneself in the participants' narratives may help sensitize counsellors working with clients from this demographic. Considering the concerns and developmental tasks of emerging adults with T1D may familiarize counselors with the unique challenges potential clients face. Yet, as with all clients, counsellors must respond to the individuals in front of them, rather than relying on preexisting assumptions or stereotypes. There are also individual differences within groups, meaning that the needs of one person with T1D may be very different than those of another.

A greater understanding of how T1D influences each client's embodied lived experiences and meaning-making processes can help counsellors and other health professionals to develop, and continually adapt, individualized treatment plans. As Chiang, Kirkman, Laffel, and Peters (2014) assert, an individualized care plan is necessary at any age. T1D care is an iterative process in which care providers must adapt their practices to support clients as they evolve and their physical and psychological needs change.

Perhaps most importantly, this research elucidates the complex psychosocial reactions of emerging adults adapting to life with T1D. It demonstrates how thoughts, beliefs, feelings, and interpersonal interactions can either encourage or impede successful diabetes self-management. Results highlight the critical need for psychological support to be included in routine disease management, supporting individuals in making healthy choices and addressing the challenges that interfere with effective self-management.

Hospitals and community clinics already offer group programming to educate patients on lifestyle adjustments that improve physical outcomes of diabetes (e.g., carb counting workshops). Similarly the development of psychoeducation and process groups addressing the psychosocial impacts of living with a chronic disease may improve holistic health outcomes and increase individuals' abilities to comply with prescribed treatments. Due to the sense of confusion and isolation common among participants in this study, a group counselling format may be particularly effective in normalizing emerging adults' experiences, increasing connection, and expanding available social supports.

Conclusion

DM already affects more than 366 million people around the world, jeopardizing population health, burdening national economies, and altering the lives of individual people (Whiting, Guariguata, Weil, & Shaw, 2011). Advancements in medicine and technology have enabled people with DM to live longer lives with fewer complications, however these interventions are only as effective as individuals' abilities to implement them. DM is often comorbid with other physiological and psychological conditions that decrease people's ability to comply with prescribed medical protocols or self-manage their health. The emerging adult

demographic in particular, faces increased risks of psychological comorbidities that interfere with successful disease management (e.g., depression and eating disorders) (Chiang, Kirkman, Laffel, & Peters, 2014).

Before we can implement interventions that improve outcomes for emerging adults, we must first determine what experiences are meaningful to these emerging adults. The current research explored the lived experiences of people diagnosed with T1D during this developmental stage, endeavouring to better understand the psychosocial implications of living with chronic illness. Study findings voice the shared experiences of people adjusting to this life-altering disease, while confronted with the normative life tasks of emerging adulthood.

Based on the present research findings and relevant academic literature, I argue for the inclusion of group counselling and psychoeducation in routine disease management, in order to address the psychosociospiritual aspects of health that often go unnoticed when one is confronted with T1D, and its threat of deleterious biological effects. The current project is also consistent with the ultimate goal of supporting informed decision-making, self-care behaviors, and proactive collaboration with health professionals, so that individuals with T1D can improve their holistic health and quality of life, in a cost-effective manner.

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Diagnosed with **type 1 diabetes** between ages 18-30?

Share your story!

A UBC M.A. Counselling Psychology student is looking for participants to share their experiences of living with type 1 diabetes.

Your participation would involve a **60-minute telephone interview**, in which you will be asked to recall experiences related to your type 1 diabetes diagnosis, and to describe your thoughts, feelings, and actions.

To ensure you are represented accurately, you will have the opportunity to provide feedback on the researcher's analysis of your interview, which will require no more than 30 minutes.

You will receive a \$25 VISA gift card in appreciation of your contribution.

Eligibility

1. You received a clinical diagnosis of insulin-dependent, type 1 diabetes between ages 18-30.
2. You were diagnosed within the past 3 years, and have maintained this diagnosis since.
3. You can read, write, and converse with ease in English.

If you meet the criteria above and would like to learn more, please contact Tanya Jakobsen at:

*****@****.com or (604) ***-****



This thesis research is conducted in partial fulfillment of UBC's M.A. Counselling Psychology Program, supervised by Dr. Colleen Haney. Department of Educational & Counselling Psychology, and Special Education, The University of British Columbia – Point Grey Campus Neville Scarfe Building, 2125 Main Mall, Vancouver, BC, V6T 1Z4

Appendix B: Letter of Initial Contact (Hospitals)



Department of Educational & Counselling Psychology, and Special Education
The University of British Columbia – Point Grey Campus
Neville Scarfe Building, 2125 Main Mall, Vancouver, BC, V6T 1Z4

Letter of Initial Contact: Hospitals

Dear Dr. _____,

My name is Tanya Jakobsen and I am a graduate student in UBC's M.A. Counselling Psychology Program. Having been diagnosed with type 1 diabetes two and a half years ago, I am now well acquainted with the diabetes clinic at _____ Hospital. My gratitude to the caring service providers and interest in improving health care, has motivated me to pursue diabetes research.

To satisfy my master's program's thesis requirement, I have chosen to conduct a qualitative study that investigates the experiences of people diagnosed with type 1 diabetes, in the stage of life known as, "emerging adulthood" (ages 18-30). Participation in the study involves attending a 60-minute interview in which participants will be asked to recall experiences related to their diagnosis and subsequent adjustment, paying particular attention to their thoughts, feelings, and actions. Participants will also have the opportunity to provide feedback once their interviews have been analyzed, ensuring that they are represented accurately.

If granted your permission, I would love to post a flyer advertising this study in the waiting room at the diabetes clinic. Please let me know if this will be possible, or if you are interested in learning more about this study. I can be contacted at (604) ***-****, or *****@****.com.

Thank you for your time and consideration,

Tanya Jakobsen

Appendix C: Letter of Initial Contact (Young & T1)



Department of Educational & Counselling Psychology, and Special Education
The University of British Columbia – Point Grey Campus
Neville Scarfe Building, 2125 Main Mall, Vancouver, BC, V6T 1Z4

Letter of Initial Contact: Young & T1

Dear _____ and _____,

My name is Tanya Jakobsen and I am a graduate student in UBC's M.A. Counselling Psychology Program. Having been diagnosed with type 1 diabetes two and a half years ago, I first became aware of your organization upon attending last year's Unspoken Truths conference. This excellent event introduced me to the lively community of T1s in Vancouver, and stoked my interest in conducting diabetes research.

To satisfy my master's program's thesis requirement, I have chosen to conduct a qualitative study that investigates the experiences of people diagnosed with type 1 diabetes, in the stage of life known as, "emerging adulthood" (ages 18-30). Participation in the study involves attending a 60-minute interview in which participants will be asked to recall experiences related to their diagnosis and subsequent adjustment, paying particular attention to their thoughts, feelings, and actions. Participants will also have the opportunity to provide feedback once their interviews have been analyzed, ensuring that they are represented accurately.

I am hoping that you could extend an invitation to participate in this study to fellow members of Young & T1, via e-mail. If this is possible, or you would like to learn more about this research project, please contact me at (604) ***-****, or tanya.jakobsen@gmail.com

Thank you for your time and consideration, as well as the hard work you do to build community among T1s!

Take care,
Tanya

Appendix D: Consent Form



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Consent Form **Experiences of Type 1 Diabetes Diagnosed in Emerging Adulthood**

Principal Investigator: Dr. Colleen Haney, Department of Educational and Counselling Psychology, and Special Education, Faculty of Education, UBC
tel.: (604) ***-****, e-mail: *****@****.ca

Co-Investigator(s): Tanya Jakobsen, Graduate Student, Department of Educational and Counselling Psychology, and Special Education, Faculty of Education, UBC
tel.: (604) ***-****, e-mail: *****@****.com

Sponsor:

This unfunded research is conducted in partial fulfillment of UBC's M.A. Counselling Psychology Program requirements. Findings of this research will be published in a graduate thesis, which is a public document.

Purpose:

The purpose of this study is to better understand the subjective experiences of people diagnosed with type 1 diabetes, during the stage of life known as emerging adulthood (ages 18-30). Results of this study will be used to inform the development of interventions that improve psychological and social outcomes for people with type 1 diabetes. You have been invited to participate in this study due to your age, and the timing of your diagnosis.

Study Procedures:

You are invited to participate in a 60-minute, semi-structured interview, in which you will be asked to recall experiences related to your type 1 diabetes diagnosis, and the time between this diagnosis and your participation in this study. Prior to publication, you will have the opportunity to provide feedback on the researcher's summary of your interview. This ensures that you are represented accurately, and will take a maximum of 30 minutes.

All telephone interviews will be audio recorded, & any in-person interviews will be video & audio recorded. Recordings will be saved on password protected DVDs. These recordings will be stored in locked filing cabinets at UBC, and accessed by the principal investigator, co-investigator, and thesis advisory committee (consisting of two UBC faculty members).

Potential Risks:

This study poses no obvious risks to physical safety, and minimal psychological risk. You will be asked to describe experiences related to your type 1 diabetes diagnosis, and subsequent experiences. For some, this could evoke uncomfortable emotions temporarily. A list of local counselling references will be given to each participant

Appendix E: Demographic Questionnaire



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Demographic Questionnaire **Experiences of Type 1 Diabetes Diagnosed in Emerging Adulthood**

Please answer the following questions to the best of your ability.

1. What is your age? _____
2. What is your gender? _____
3. Describe your ethnic background: _____
4. What is your first spoken language? _____
 - a. What language do you speak at home? _____
5. In what city do you live? _____
6. How many people (including yourself) share this home? _____
 - a. What is your relationship to each? _____
7. What is your occupation? _____
8. What is the highest level of schooling you have completed?

9. When did you first receive a type 1 diabetes diagnosis? _____
10. If you had symptoms prior to diagnosis, please list them:

11. Before your diagnosis, what did you know about diabetes?

Appendix F: Interview Schedule



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Interview Schedule **Experiences of Type 1 Diabetes Diagnosed in Emerging Adulthood**

1. Thinking back to when you first thought you had this disease, describe your experiences since then. What did you think, feel, and do?

Example prompts may include:

- Tell me more about that...
 - Can you describe that in more detail?
 - When you said x, would you clarify what you meant by that?
2. Thank you for the feedback you've provided, before we end, is there anything you'd like to add?

Appendix G: Counselling Services List



Department of Educational & Counselling Psychology, and Special Education
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Reduced-Cost Counselling Services in Greater Vancouver

Here is a list of local counselling services that you can reference if you want to find someone to talk to, about whatever is on your mind.

Scarfe Counselling - UBC - 604-*-**** - FREE**

<http://ecps.educ.ubc.ca/cnps/scarfe-counselling-clinic>

Counselling is provided by counselling psychology graduate students, and supervised by a psychologist.

Clinic runs from September to April.

New Westminster UBC Counselling Centre - 604-*-**** - FREE**

<http://ecps.educ.ubc.ca/clinical-instructional-resources/new-westminster-ubc-counselling-centre/>

Counselling is provided by counselling psychology graduate students, and supervised by a psychologist.

Oak Counselling - 604-*-**** - SLIDING SCALE (\$10-\$65/session)**

<http://oakcounselling.org/>

Secular counselling services provided at the Vancouver Unitarian Centre by supervised volunteers with Master's degrees in psychology or psychology-related fields. Individual, couples, and family counselling are available.