Exploring the Experiences and Support Needs of Mothers of Children With Type 1 Diabetes

by

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Abstract

Background: Type 1 diabetes (T1D) accounts for approximately 10% of all diabetes cases and is an incurable, life-threatening chronic condition that poses significant practical and emotional challenges for patients and their families. Typically diagnosed during childhood, T1D requires constant vigilance to manage and reduce the risk of complications, thereby improving long-term outcomes. The primary responsibility for managing T1D typically falls on mothers, who report performing 70% of all blood glucose checks and 79% of insulin administrations. Caregivers of children with T1D describe the management as intensive, stressful, and relentless, experiencing challenges that strain their physical health, social lives, finances, and emotional well-being. These burdens are reported to be more severe and prevalent among mothers than fathers. Although previous studies have reported on the psychological consequences of caring for children with chronic diseases, no qualitative review has specifically examined the caregiving burden among parents of children with T1D. Furthermore, no qualitative studies have focused on the experiences and support needs of mothers as caregivers, especially within the Canadian context, where Canada ranks sixth among the top 10 nations with the highest rates of T1D in children. It is estimated that 1 in 300 school-aged children in Canada have T1D, which is expected to rise. **Objectives:** (a) To conduct a qualitative review to describe the experience of caregiver burden in parents of children with T1D. (b) To understand the experiences of mothers caregiving for children with T1D under the age of 18 in northern Alberta. (c) To identify the support needs of mothers in northern Alberta with a child with T1D under the age of 18. (d) To suggest clinical, social, and policy recommendations to improve the health and mental well-being of mothers of children with T1D. **Methods:** Three interrelated studies were conducted to address the objectives. Study 1: A qualitative scoping review was conducted to systematically map the literature on caregiver burden in parents of children with T1D, exploring the financial, physical, social, spiritual, and emotional or psychological challenges they face. An expert health sciences librarian executed the search strategy. This process resulted in the inclusion of 18 peer-reviewed qualitative studies, which were thematically analyzed. Study 2: Sixteen semistructured interviews were conducted with mothers in northern Alberta who care for children with T1D under the age of 18. Participants were recruited using convenience sampling through the Stollery Pediatric Diabetes Education Centre (PDEC) in Edmonton, Alberta. Data were analyzed using a qualitative descriptive approach. Study 3: Two focus groups were held to understand the support needs of mothers of children with T1D under the age of 18 in northern Alberta. Twelve participants were recruited and divided into a rural or urban focus group of six participants each. Five of these mothers were participants from Study 2; the remaining seven were recruited through convenience sampling via the PDEC. The interviews and focus groups were recorded and transcribed verbatim. NVivo 12 was used for data management and analysis. The data were coded and analyzed using thematic analysis. Studies 2 and 3 were conducted collaboratively with a Caregiver Advisory Committee comprising three mothers of children with T1D. **Results:** The scoping review identified that parents, especially mothers, experience a range of distressing emotions, with grief being a constant experience. Parents frequently navigate a heightened state of vigilance to manage glucose levels, particularly during the night. Peer support was found to reduce feelings of loneliness and serve as an informational source. Individual interviews from Study 2 corroborated these findings, adding that respite care and continuous glucose monitoring systems relieved stress among mothers in northern Alberta. Although rural and urban mothers in Alberta have similar support needs, those in rural areas reported a greater need for specialized pediatric care and financial support. Overall, mothers in northern Alberta would benefit from improved access to formal respite care, enhanced mental health services, increased financial assistance, greater social interaction opportunities, and more comprehensive school policies.

Conclusion: Ten clinical, policy, and social recommendations are presented to improve the experience of mothers caregiving for a child with T1D. Understanding their unique experiences and needs is essential for planning, improving, and advocating for services for this population. Enhanced support for mothers translates to better caregiving, diabetes management, and health outcomes for their affected children.

Preface

This thesis is an original work by Tara Azimi. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board (REB # Pro00104580). The project's name is "Exploring the Experiences and Support Needs of Mothers of Children With Type 1 Diabetes in Northern Alberta: A Qualitative Descriptive Analysis." Study participants were given detailed verbal and written information about the aims of the study and the voluntary nature of their participation. All participants gave their explicit consent.

The research was based on a scoping review of global qualitative studies exploring caregiver burden among parents with a child with type 1 diabetes (T1D; Chapter 2), a qualitative descriptive study of the experiences of mothers in northern Alberta caring for a child with T1D (Chapter 3), and two focus groups with rural and urban mothers in northern Alberta to explore their caregiving support needs (Chapter 4). The studies in Chapters 2 and 3 were conducted with guidance and advice from a Caregiver Advisory Committee, which included three mothers of children with T1D in northern Alberta. Advisory members assisted in the second study with the development of the interview guides and with insight and feedback on the coding framework and the themes generated. In the third study, they supported the cofacilitation of focus groups. The findings from the three studies in this thesis provide a detailed exploration of caregiver experiences and support needs while caring for children with T1D.

With support and guidance from her supervisors, Drs. Stephanie Montesanti and Jeffery Johnson, Ms. Azimi led each of the three studies (e.g., developed the study protocol, implemented the research, analyzed the data, mentored a master's student to support data extraction for the scoping review, interpreted the findings, and prepared the manuscript). The

PhD supervisory committee (Dr. Stephanie Montesanti, Dr. Jeffery Johnson, Dr. Richard Oster, and Ms. Lisa Wozniak, who are coauthors on each study, provided constructive feedback and reviewed each chapter. They also provided insight and feedback on the coding framework and the themes generated for Studies 2 and 3. In particular, Dr. Montesanti helped with the initial development and planning of each study and provided financial support for data collection and manuscript publication. Dr. Johnson assisted with establishing connections with leading experts in childhood and adolescent diabetes for additional mentorship.

Chapter 2 has been published as follows:

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Chapter 3 (Study 2) is currently under review in the journal *BMC Public Health* as follows:

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Chapter 4 (Study 3) has been submitted to the journal of *BMC Women's Health* as follows:

Azimi, T., Wozniak, L. A., Oster, R. T., Johnson, J., & Montesanti, S. (2024). Exploring the support needs of mothers of children with type 1 diabetes in northern Alberta. *BMC Women's Health*. (Submitted August 2024).

Dedication

To my parents, without whom I would not have begun.

To my supervisors, without whom I would not have finished.

To the maternal caregivers of children with T1D. Know that you are strong, admired, and heard.

Acknowledgements

Completing this PhD dissertation has been a journey filled with challenges, growth, and countless moments of inspiration. I am deeply grateful to everyone who has supported me along the way.

To my parents, Parvin and Khosro, thank you for raising me to believe in myself in any context and despite any challenges, and for encouraging my love of learning and my pursuit of education. Thank you for all your sacrifices, which have allowed me to chase my dreams comfortably. Without your unconditional love, support, and encouragement, I would not be where I am today.

To my supervisors, Dr. Stephanie Montesanti and Dr. Jeffery Johnson, I wish to express my heartfelt gratitude for your unwavering support, astute guidance, and encouragement. You have been instrumental in shaping this research and in my achievements as a graduate student. Dr. Montesanti, your expertise and dedication to my academic and personal growth have made this journey not only possible but also profoundly enriching. I am grateful for the diverse work experiences, financial support, and training opportunities you provided. I also appreciate the thoughtful discussions we've had, which refined my research and broadened my perspective. You have not only helped me recognize my strengths and prepared me to be a better researcher, but also provided the inspiration and insight I needed to overcome my challenges. Dr. Johnson, your ability to see the broader implications of my work and your efforts to connect me with leading experts for additional mentorship immensely enhanced the quality of this research. Your practical guidance, dedication to answering my countless questions, and constructive feedback helped me maintain momentum and remain determined to strive for excellence.

I would also like to acknowledge my incredible thesis committee members, Lisa Wozniak and Dr. Richard Oster. Lisa, not only did you provide invaluable insights, but your guidance and encouragement were integral in helping me stay focused and motivated. I am grateful for your keen eye for detail and your enthusiasm to always support me. Richard, your inquisitive approach challenged me to think critically and stay self-aware, which improved my research and perspective. Thank you both for your dedication throughout this process.

To my advisory committee members and the participants of this study, thank you for sharing your experiences and opinions so openly. Your contributions have been the heart of this research, and without your willingness to participate, this work would not have been possible. Your stories and experiences have inspired me and added depth and meaning to this dissertation.

A special thanks to my siblings, peers, and friends, who have been my constant companions throughout this journey. Your encouragement, patience, and understanding have been a source of immense comfort and motivation. You have celebrated my successes and lifted me up during challenging times, reminding me of the reasons I embarked on this journey. For that, I am eternally grateful. I would also like to acknowledge everyone who has supported me in ways both big and small. Your kindness and belief in me have made this achievement possible. Thank you for being a part of this journey and for helping me reach this significant milestone.

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List of Abbreviations

CASP	Critical Appraisal Skills Programme
CGM	Continuous glucose monitor
DOC	Diabetes online community
EA	Educational assistant
FCC	Family-centred care
ICP	Individual Care Plan
IDF	International Diabetes Federation
PDEC	Pediatric Diabetes Education Centre
PTSD	Posttraumatic stress disorder
QD	Qualitative descriptive
T1D	Type 1 diabetes
T2D	Type 2 diabetes

Chapter 1: Introduction

Chronic, noncommunicable diseases are on the rise worldwide and are the leading causes of disability and death. In 2016, chronic diseases contributed to 40.5 million deaths, roughly 71% of the global deaths for which a cause was identified (World Health Organization, n.d.). Although adults and the aging population are mainly affected, a significant number of children are also impacted by chronic diseases each year (Adib-Hajbaghery & Ahmadi, 2019; Kish et al., 2018). One of the most devastating and challenging chronic diseases diagnosed during childhood and early adolescence is type 1 diabetes (T1D). Presently incurable, T1D is on the rise nationally and internationally (Norris et al., 2020). Unlike type 2 diabetes (T2D), which is attributed in large part to lifestyle factors such as poor diet, a lack of exercise, and excess body weight, T1D is a genetic and immune-mediated condition that leads to the destruction of insulin-producing beta cells in the pancreas, requiring lifelong insulin (Diabetes Canada, 2023b).

According to the International Diabetes Federation (IDF), one individual worldwide dies from diabetes or its complications approximately every seven seconds (IDF, 2017). Nearly 1.6 million deaths were directly attributed to diabetes in 2016 (World Health Organization, 2020). Using high-quality data sources from 138 countries and extrapolated estimates for countries without quality data, analysis from the IDF indicated that globally, 463 million people, or 9.3% of the population—nearly half a billion individuals—were living with diabetes in 2019 (Saeedi et al., 2019). Findings from the most recent *IDF Diabetes Atlas* indicate that the global prevalence of diabetes will continue to rise (Saeedi et al., 2019): It is estimated to rise to 10.2% (578 million people) by 2030 and to 10.9% (700 million people) by 2045. This increase is nearly seven times the prevalence rate compared to the 1980s, when 108 million people had diabetes globally (World Health Organization, 2020).

Although rates of T1D specifically are not well documented across all regions or among different populations, T1D is estimated to account for 10% of all diabetes cases, with incidence rates increasing by 3%–4% yearly (Hex et al., 2012; Norris et al., 2020; Saeedi et al., 2019). According to Patterson et al. (2014), approximately 80,000 children develop T1D each year globally. The most substantive T1D increases are in children under the age of 5 (Atkinson et al., 2014; Patterson et al., 2014). Extrapolated global estimates place Canada sixth among the top 10 countries with the highest rates of T1D in children under the age of 15 (per 100,000), surpassing the United States, which ranks 10th, and following the Scandinavian countries of Finland, Sweden, and Norway, which are burdened with the highest incidence rates (Patterson et al., 2014). Approximately 1 in 300 children and youth under the age of 19 have T1D in Canada (Alberta Education, 2019). In Alberta, roughly 403,000 people, 8% of the population, are diagnosed with diabetes, and 5%–10% of those Albertans are living with T1D. The prevalence of individuals diagnosed with T1D and T2D in Alberta is projected to increase by 41% from 2023 to 2033, highlighting it as a growing health concern that necessitates ongoing attention (Diabetes Canada, 2023b).

Whereas most autoimmune conditions disproportionally affect women, T1D is slightly more common among men (Atkinson et al., 2014) and it generally presents itself between the ages of 5 and 7 or around puberty (Atkinson et al., 2014). However, trends in Canada indicate that the most significant increase in incidence is among individuals 10 to 14 years of age (Fox et al., 2018).

Living with T1D exacerbates risks for long-term health complications such as kidney failure, neuropathy, and cardiovascular disease; these complications increase medical expenditures for the patient and accrue substantial costs and demands on health care systems

(Atkinson et al., 2014; Centers for Disease Control, 2011). In Canada, the direct cost to the health care system in 2020 was estimated to be $3.8 billion for T1D and T2D combined, an expense that is expected to increase to $4.9 billion by the year 2030 (Diabetes Canada, 2023b). Out-of-pocket costs for people living with T1D vary from a low of $78 to a high of $18,306 annually in Canada's provinces (Diabetes Canada, 2022b). Residents with T1D in Alberta, for example, pay nearly 9% of their gross annual income towards equipment and medications (Diabetes Canada, 2023b). The costs associated with treatment options vary widely based on the patient's needs, preferences, and means. Patients may use a combination of multiple daily injections and capillary blood glucose monitoring, insulin pumps, and continuous glucose monitors (CGMs).

Provinces in Canada offer varying levels of financial support for medical supplies and technology to individuals with T1D (Diabetes Canada, 2021a). For example, since 2021, the Alberta government has provided coverage for diabetes supplies for individuals on government-sponsored drug programs. This coverage ranges from $160 to $320 annually and includes items such as needles, syringes, lancets, blood glucose meters, blood ketone meters, and urine testing strips (Diabetes Canada, 2021a). Furthermore, effective February 2022, insulin-dependent Albertans under the age of 18 enrolled in a government-sponsored health benefit program are eligible to claim the cost of a CGM. The number of CGM transmitters covered depends on the type of CGM being used, and eligibility for the CGM benefit is contingent on a prescription from an endocrinologist or pediatrician (Diabetes Canada, 2023a). Alberta also offers a comprehensive Insulin Pump Therapy Program that covers the cost of insulin pumps and supplies for residents with T1D who meet specific eligibility criteria. Eligible participants can receive a new insulin pump every 5 years, contingent upon recommendations from an endocrinologist. The program is available to individuals of all ages without income testing (Diabetes Canada, 2024).

While coverage of glucose monitoring devices is included in many private insurance plans, public coverage is inconsistent across Canada. For example, Nova Scotia residents with T1D do not have coverage for CGMs. Additionally, in contrast to Alberta's Insulin Pump Therapy Program, the Newfoundland and Labrador Insulin Pump Program requires medically eligible individuals aged 25 and over to undergo an income review to determine eligibility for financial support (Diabetes Canada, 2024). This requirement can create barriers for those who do not qualify based on income but may still face significant financial burdens due to the cost of diabetes management. Additionally, the administrative process associated with income testing may deter some individuals from applying for or receiving timely assistance. Insulin pumps in Canada can cost from $6,000 to $7,000 (Diabetes Canada, 2021b). Limitations on access to insulin pump therapy and CGMs may translate to poorer glucose management, diabetes treatment satisfaction, and quality of life. For example, a U.S.-based study by Foster et al. (2019) found that the use of CGMs among individuals under the age of 13 reduced their A1C levels (average blood glucose levels over 3 months) by 1% compared to self-monitoring of blood glucose. Diabetes Canada (2021b) has advocated for provincial governments to ensure equal access to insulin pump programs for individuals with T1D, regardless of age-based restrictions and other financial and administrative obstacles.

Caregiving Experience

Despite advances in medical knowledge that have led to improved diagnosis, treatment, and lower early fatality rates, managing T1D in children remains particularly complex (Kish et al., 2018). Because T1D is often diagnosed during childhood, parents play a crucial role in preventing short- and long-term health issues, managing their child’s condition, and ensuring their well-being. For individuals with T1D, lifelong insulin replacement is required, and their health outcomes are highly dependent on the ability to manage blood glucose levels effectively (Atkinson et al., 2014). Maintaining near-normal glycemic control is associated with better long-term health outcomes, reduced risk of chronic complications, and improved life expectancy; in contrast, failing to prevent severe hypoglycemic episodes (low blood glucose) can cause altered mentation, seizures, loss of consciousness, and death (Atkinson et al., 2014). Therefore, parents of children with T1D take on numerous responsibilities, including monitoring their child's physical activity, diet, and blood glucose levels, as well as administering insulin. Additionally, they must advocate for their child's health needs, support the transition of responsibility as their child grows, cover medical expenses, learn to use T1D management devices, and foster a sense of normalcy and security to help their children cope with the psychological aspects of the illness (Landolt et al., 2005; Sullivan-Bolyai et al., 2003).

The literature on T1D and caregiving experience emphasizes the various stressors involved in managing a child’s care needs. For example, Landolt et al.’s (2005) study of recently diagnosed children with T1D found that approximately 25% of mothers and fathers met the criteria in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*; American Psychiatric Association, 2000) for posttraumatic stress disorder (PTSD) 6 weeks postdiagnosis. Other studies have found increased sleep disturbance due to nighttime worries related to diabetes and glucose monitoring (Feeley et al., 2019; Herbert et al., 2015). In a study on sleep with 500 parents of children with T1D, Jaser et al. (2017) indicated that 53% of the participants met the criteria for poor quality of sleep. Additionally, 50% of those participants reported sleeping less than the recommended 7 to 9 hours (Jaser et al., 2017).

Parents of children with T1D also experience financial challenges. According to a 2011 report from the Centers for Disease Control, the cost of caring for a child with T1D in the United States was six times higher than the cost of caring for a child without diabetes. Children without diabetes were noted to have annual medical expenses of roughly USD $1,400, whereas the medical costs for a child with diabetes were estimated at more than USD $9,000. The report attributed the high costs of medical care to insulin treatment to control glucose levels (Centers for Disease Control, 2011). Similar estimates for children with diabetes in Canada are not available. That said, the Royal Commission on the Future of Health Care in Canada (Romanow, 2002) defined the threshold for catastrophic drug costs as 3% of gross income. In 2022, over half the individuals in Canada with T1D either exceeded this threshold or, due to the prohibitive cost, failed to adhere to the treatment recommended by their doctor (Diabetes Canada, 2022). Suboptimal diabetes management, the cost of healthier food choices, more recurrent visits to the doctor, and efforts to prevent complications can exacerbate the costs of caring for a child with T1D (Centers for Disease Control, 2011; Cox et al., 2020). These challenges may be more apparent for families with lower socioeconomic status, which has been correlated with higher financial burden when caring for a child with a chronic disease (Eshtehardi et al., 2021).

Caregiving Experience Related to Developmental Transitions

The experience of caregiving is also influenced by the developmental transitions of a child (Karlsson et al., 2008). Diabetes care encompasses a greater consideration for behavioural aspects of development, arguably more than other chronic diseases. For instance, Hatton et al. (1995) found that as young children cognitively matured, their need for independence and self-assertiveness led to manipulation to avoid disease management routines. Physical strength in growing toddlers resulted in conflict over invasive procedures and physical defiance. Also, growth in cognitive development resulted in children engaging in verbal impudence and expression of detest for injections, which parents found heartbreaking (Hatton et al., 1995). Streisand and Monaghan (2014) described a period of physical development through the age of 6, during which children engage in frequent and inconsistent bursts of physical activity, requiring increased glycemic monitoring and resulting in increased apprehension for parents over potential hypoglycemic episodes. Physiologically, young children may be more prone to significant fluctuations in blood glucose levels due to their unpredictable food intake and exercise patterns, as well as an increased sensitivity to insulin (Streisand & Monaghan, 2014). Socially, children may also become more interested in play dates around this age, requiring parents to teach others about T1D treatment and how to recognize signs of high or low glucose levels. Parents may need to be prepared for potential emergency calls and pick-ups, leading to further emotional angst (Streisand & Monaghan, 2014).

The balance and transfer of caregiving responsibilities as maturing children assume more accountability for diabetes-related tasks is also a psychologically burdensome time for caregivers. A young adolescent's ability and willingness to maintain metabolic control and good health, and potential inconsistencies in self-care, are commonly reported sources of anxiety and stress among caregivers (Tomette et al., 2020). Self-management of T1D among adolescents is further complicated by normative psychosocial, emotional, sexual, and cognitive development, as well as socialization, experimentation, and rebellion (Streisand & Monaghan, 2014; Whittemore et al., 2012). For caregivers, these "normative developmental issues have an added layer of complexity because critical short- and long-term health and safety implications are directly linked with the adolescent's lifestyle and performance of multiple daily DM [diabetes mellitus] management tasks" (Mellin et al., 2004, p. 221). For instance, caregivers of teenagers with T1D report anxiety over their children experimenting with alcohol and not following dietary advice when among friends or at social gatherings (Silverstein et al., 2005). Tomette and colleagues (2020) found that caregivers experienced a significant increase in distress even when their child with T1D entered the developmental stage of emerging adulthood (ages 18 to 25), a period during which children are typically expected to practice self-care and parental distress is expected to decrease. This increase in distress suggests that parental concern for caring for a child with T1D is an ongoing experience.

Gender and Caregiving for Children With T1D

Often conflated with the biologically based category of sex, gender refers to the socially prescribed and experienced dimensions of femaleness or maleness (Johnson et al., 2009). Pertinent to this idea is the concept of gender roles, which are the behavioural norms applied to males and females in society. In some cultures, roles are distinctly differentiated, defining and ascribing what tasks, jobs, or opportunities pertain to men versus women. As such, gender roles categorize individuals within the labour force or the institution of the family, for instance, and impact everyday actions and the contributions individuals make as men or women (Johnson et al., 2009).

In the literature on caregiving, it is well established that women take on the majority of the caregiving role for chronically ill family members, be it for their children, a parent, or their spouse (Himes, 1994). By virtue of this tendency, researchers have concluded that the experience of caregiving is gendered (Calasanti & Kiecolt, 2012; Ghosh et al., 2020). In a study investigating caregiver burden in relation to gender and family relationships among 535 multicultural (predominantly Latino) caregivers, Friedemann and Buckwalter (2014) found that unlike men, women viewed caregiving duties as an extension of their usual role. Caregiving was seen as an expectation of society and their family. Women felt guilty about giving less of themselves and therefore felt more stressed and took on a greater overall caregiving burden compared to men (Friedemann & Buckwalter, 2014).

Another study that similarly examined the burden of caregivers of adults with multiple chronic conditions investigated the intersectionality of gender, age, education level, and employment status, as well as its impact on social life (Ghosh et al., 2020). The overall results of the five-way interaction of the variables revealed higher burden scores for women in all categories compared to men. Highly educated females who were employed indicated one of the highest burden rates. Concurring with findings from Williams et al. (2016), Ghosh and colleagues (2020) concluded that combined pressures from work, family life, and caregiving duties can have a negative impact on female caregivers. This finding is not surprising given that although women make up half of the workforce, they are still expected to undertake most caretaking responsibilities (Versey, 2017).

Based on the studies mentioned earlier, in the context of T1D, even though the responsibility of caring for a child with T1D can affect the entire family, data indicate that traditionally, mothers have predominantly assumed the role of the primary caregiver (Meleski, 2002; Wysocki & Gavin, 2006). Mothers of children with T1D report being relied on as the main decision-maker and consistent treatment provider for their children by both health care professionals and their spouses (Lindström et al., 2017; Streisand & Monaghan, 2014). In multiple studies, fathers have credited essential caregiving tasks to their wives and identified them as being a source of support and assistance to them, or a “caregiver to the caregiver.” They felt more trusting of their wives’ capabilities and questioned their own knowledge and caregiving skills (Coffey, 2006; Cousino & Hazen, 2013; Sullivan-Bolyai et al., 2006).

Due to a greater commitment to the caregiving role, caregiving stressors are also expected to be different and more pronounced-for mothers of children with T1D compared to fathers (Adib-Hajbaghery & Ahmadi, 2019; Meleski, 2002). For example, in the abovementioned study by Landolt et al. (2005), even though both mothers and fathers met the *DSM* criteria for PTSD (American Psychiatric Association, 2000), mothers reported significantly greater severity of symptoms. Mothers also had a higher prevalence of PTSD compared to fathers both at 6 weeks and at 12 months, and whereas the prevalence of PTSD for fathers decreased over time, it rose for mothers (Landolt et al., 2005). Other studies examining the association between factors such as emotional distress, physical burden, or occupational stress with demographic and clinical features have also revealed a higher burden among mothers compared to fathers (Dehn-Hindenberg et al., 2021; Haugstvedt et al., 2011; Saßmann et al., 2022).

Caregiver Support Needs

Given that caregivers experience various challenges, it is crucial to consider their support needs to alleviate caregiver distress. Whereas the management of T1D in children can disrupt family practices and requires constant care (Whittemore et al., 2012), “studies of the effects of children’s chronic illnesses on parents have shown that stressors aren’t solely related to a particular disease” (Meleski, 2002, p. 51), but rather are related to the demands, lack of knowledge, adaptation, worries over long-term health complications, and transition of care involved. Thus, equipping caregivers with the skills necessary to manage T1D and fostering positive interactions, education, and personalized support from medical professionals can improve psychological well-being and reduce experiences of caregiver burden among parents of children with T1D (Rankin et al., 2016).

In a study by Commissariat et al. (2020), parents identified that gaining comprehensive information about both acute and chronic complications would provide them with the tools to "avoid the worst-case scenario" (p. 381). Howe et al. (2012) noted that anticipatory guidance from health care providers for developmental considerations and tailored diabetes regimens aligned with a family's lifestyle were also important expectations parents had as they navigated their caregiving role. Such guidance bolstered parents' self-confidence and positivity (Howe et al., 2012). In another qualitative study about parents' support and information needs with 54 parents of children with T1D, Rankin et al. (2016) concluded that parents needed more reassurance from health care professionals after their child was diagnosed. Participants in their study who had received reassurance felt that it placed them in a better psychological and emotional position to absorb disease management information.

In addition to professional support from health care providers, peer support has been found to promote positive health outcomes in caregivers. Online communities, including Facebook group pages, blogs, and forums, have become popular platforms for peer support. In fact, *diabetes online community* (DOC) is a rapidly growing and widely used term to describe people living with T1D and their families, who engage in various online support activities and web-based platforms (Hilliard et al., 2015). Participation in the DOC can include activities such as "creating and contributing original content, collating and reposting others' content, commenting on or responding to others' content, and/or observing and consuming others' content" (Hilliard et al., 2015, p. 262). The most common reasons patients and their caregivers engage with the DOC are to seek social connection and emotional support, to discuss technology and device use, to learn about and share medical information, and to share personal stories, successes, and challenges (Hilliard et al., 2015). Findings by Balkhi et al. (2014) suggest that individuals using DOC forums place a significant amount of trust and value in the relationships created online and in the information they receive, affecting how they provide care to their child with T1D.

The prevalence of T1D among children, estimated at approximately 1 in 300 in Canada (Alberta Education, 2019), underscores the likelihood that most educational institutions will encounter students with this condition. Given that students typically spend 6–8 hours daily in the school environment, where blood glucose fluctuations are common, the implementation of robust school-based support systems for children with T1D is crucial for alleviating parental worry, maintaining continuity of care, and optimizing glucose control. Both hypoglycemic and hyperglycemic episodes can significantly impact cognitive function, behaviour, academic performance, and learning capacity (Lawrence et al., 2015; Semenkovich et al., 2016). Therefore, the presence of trained staff to support students in managing potential blood glucose highs and lows during school hours is paramount. This support not only mitigates the need for caregivers to disrupt their professional or personal commitments to provide diabetes-related assistance at school, but also ensures that children with T1D can fully engage in and benefit from the educational experience.

Adequately trained school personnel can play a vital role in facilitating the comprehensive inclusion of students with T1D in all aspects of school life, such as participation in physical education, field trips, and extracurricular activities, thereby promoting a sense of normalcy, equal opportunity, and improved mental well-being for these students (Lawrence et al., 2015). In Canada, the implementation of Individual Care Plans (ICPs) for children with T1D aims to ensure that children can fully engage in school activities while effectively managing their condition (Diabetes Canada, n.d.). An ICP is a comprehensive document that delineates the specific needs and management strategies for a child with T1D in educational settings (Alberta Education, 2019; Diabetes Canada, n.d.). These plans are typically developed through a collaborative effort involving the child's parents or guardians, health care providers, and school personnel. The ICP encompasses crucial information such as blood glucose monitoring protocols, insulin administration guidelines, meal planning, and emergency procedures (Diabetes Canada, n.d.). However, the implementation of ICPs varies significantly across provinces and little research exists on the utilization and evaluation of ICPs across Canada (Alberta Education, 2019; Diabetes Canada, n.d.).

Practical supports such as the use of diabetes technologies like a CGM or insulin pump have also been associated with lower parental stress by improving nighttime monitoring and control and reducing fear of hypoglycemic events (Hilliard et al., 2015). Additionally, the availability of respite relief from extended family and friends and the availability of support and understanding from an individual’s social community can also alleviate stress among caregivers. For example, in a study by Haugvik et al. (2017) on children with T1D in Tajikistan, parents described obstacles to acceptance of their child’s disease in their community. They described experiencing stress, stigma, discrimination, and diabetic complications as a result. A negative or unsupportive response from one’s community can affect how caregivers internalize and experience their child’s chronic condition and their social experience.

Importance of Providing Supports to Maternal Caregivers

Adequate support for mothers can enhance their ability to cope with daily caregiving challenges, reduce stress, and improve their overall well-being. Additionally, well-supported mothers are better equipped to provide adequate care for their children, leading to improved health outcomes for both the child and the family (Anderson & White, 2018; Rechenberg et al., 2017). Models of parent–child dyadic coping suggest that a bidirectional impact may take place in caregiving, where the illness affects the family and the caregiver's stress and perceptions of the caregiving burden affect the child's health-related outcomes (Anderson & White, 2018). According to Pierce et al. (2017), caregiving for a child with T1D "poses affective, behavioral, and cognitive demands for parents, and their responses may predict later T1D outcomes" (p. 19). For instance, studies on the management of T1D in children from the ages of 7 to 17 and 10 to 17 have associated greater parenting stress with deteriorating glycemic control management, which consequently raises the risk for short- and long-term disease-related complications (Cousino & Hazen, 2013; Rechenberg et al., 2017). In addition, numerous studies have recognized links between caregiver mental health and adverse child psychological sequelae. For instance, maternal stress has been associated with depressive symptoms in youth with diabetes. Mental health conditions such as depression are commonly linked to poorer quality of life as well as poorer metabolic control in children with diabetes (Rechenberg et al., 2017).

Additionally, maternal coping styles have been correlated with coping styles adolescents adopt (Rechenberg et al., 2017). Positive maternal coping has been associated with improved self-management behaviours and positive peer relations among young people with T1D. Alternatively, poor coping adaptations, restrictive parenting, and depressive symptoms or PTSD in mothers have been linked to depressive symptoms and poorer transition towards T1D self-management in their children (Karlsson et al., 2008; Rechenberg et al., 2017). According to Rechenberg et al. (2017), successful emotional adjustment is enhanced in persons with chronic diseases receiving care when they perceive healthy coping and emotional support from the caregiver. As such, collectively, researchers support the conclusion that maternal mental health is a critical constituent of mental health and adjustment in children and youth with T1D (Rechenberg et al., 2017).

Diversity of Support Needs

Although all mothers as caregivers require support, the diversity of the family structure must also be considered, including its composition (e.g., single-parent households, married partners; Kazak & Christakis, 1994). For instance, when analyzing parental adjustment in long-term survivors of cancer, Kazak et al. (2001) found that family structure variables, such as being a single parent, being a younger parent, and having four or more children, were indicative of reduced resources and higher caregiver stress. In Canada, single-parent families face significant financial challenges compared to two-parent families. Financial resources available to single parents are considerably lower, with lone-parent families often experiencing higher poverty rates (Statistics Canada, 2015). According to researchers, lower income levels are associated with poorer physical and psychological health among caregivers of children with chronic illnesses (Raina et al., 2005). These findings are significant given that the proportion of children in two-parent families has decreased, and most single-parent families in Canada are led by mothers (Gucciardi et al., 2004). It is reasonable to assume that these aspects of the family unit could affect how family members and caregivers would function and cope when caregiving for a child with T1D.

A further consideration is that access to supports and the types of supports required may differ depending on demographic variables such as residence in rural versus urban areas. For example, rural areas often have fewer health care facilities and pediatric specialists compared to urban regions, leading to longer travel distances for medical appointments and possibly delaying access to emergency medical services (Caldwell et al., 2016; Dewan & Cohen, 2013). Rural areas also often have lower average incomes and higher poverty rates, which affect the ability to afford care and support services (Statistics Canada, 2020). More limited job opportunities in rural areas than in urban centres may make it difficult for caregivers to find flexible employment that accommodates caregiving responsibilities (Hay et al., 2006; Stumetz et al., 2016), adding to their financial challenges. Alternatively, it can also be argued that higher living costs in urban areas than in rural areas can create economic pressures for residents. Furthermore, even though rural communities can offer stronger personal networks compared to urban communities, these networks may not always meet the specific needs of chronic illness care, leading to greater isolation due to fewer health-specific support groups and community resources (Hay et al., 2006). In contrast, urban centres generally have better access to specialized pediatric services, more comprehensive health care teams, and a wider range of community support services for children with chronic illnesses. However, urban areas may face their own access challenges, such as longer wait times for services and traffic (Dewan & Cohen, 2013; Hay et al., 2006). It is, therefore, imperative to identify and assess a population's unique needs and experiences when aiming to address their support needs.

Thesis Objectives

Having a child diagnosed with a chronic and life-threatening illness such as T1D is arguably distressing and can pose many day-to-day caregiving challenges for primary caregivers (Whittemore et al., 2012). However, research on understanding the support needs and experiences of caregivers—especially mothers, who are often the primary caregivers—has been limited, especially in the Canadian context. The increasing occurrence of T1D in Canada, as well as Canada's high global ranking for T1D rates in children under 15 (Patterson et al., 2014), accentuate the necessity for targeted research on this subject. Addressing this need to help fill the knowledge gap was the foundation of my dissertation.

The project's outlined purpose was achieved through three studies presented as separate manuscripts for relevant journals.

1. “Caregiver Burden Among Parents of Children With Type 1 Diabetes: A Qualitative Scoping Review” (Chapter 2). The objective of this first study was to qualitatively investigate the multifaceted dimensions of caregiver burden in parents of children with T1D by exploring the financial, physical, social, spiritual, and emotional or psychological stressors they have experienced. This chapter provides an overview of the current literature on caregiving experience.
2. “Exploring the Experiences of Mothers of Children With Type 1 Diabetes in Northern Alberta: A Qualitative Descriptive Study” (Chapter 3). The objective of this second study was to understand the maternal experiences of caring for a child under the age of 18 with T1D in northern Alberta.
3. “Exploring the Support Needs of Mothers of Children With Type 1 Diabetes in Northern Alberta: A Qualitative Descriptive Analysis” (Chapter 4). The objectives of this final study were to understand (a) the support needs of mothers in northern Alberta living with children with T1D under the age of 18, and (b) the similarities and differences in the support needs of mothers in rural and urban Alberta.

Chapter 5 is the concluding chapter, discussing an overall summary of the three research projects. It also provides clinical, social, and policy recommendations and suggestions for future research.

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Chapter 2: Caregiver Burden Among Parents of Children With Type 1 Diabetes: A Qualitative Scoping Review

This study was a qualitative investigation of the multifaceted dimensions of caregiver burden in parents of children with T1D. My coauthors were Jeffery Johnson, Sandra Campbell, and Stephanie Montesanti. The manuscript was published in March 2024 in *Heliyon*. To fit this dissertation, I have reduced major headings by one level, and I have included the chapter number in the figure and appendix numbering. No other changes have been made to the original submission.

Chapter 2 Abstract

Objectives: Type one diabetes (T1D) in children places substantial responsibility on parents as caregivers. This study investigated caregiver burden in parents of children with T1D by exploring the financial, physical, social, spiritual, and emotional or psychological problems they experienced. **Methods:** We conducted a qualitative scoping review of the databases PsycINFO, PROSPERO, OVID Medline, OVID EMBASE, Cochrane Library (CDSR and Central), EBSCO CINAHL, ProQuest Dissertations and Theses Global, and SCOPUS. Of 119 full text articles assessed for eligibility, 18 peer-reviewed qualitative studies were included. Studies were considered relevant if they focused on diabetes management and parental burden or the experience of caregiving for a child with T1D. **Results:** Using thematic analysis, six interrelated themes were identified: (a) experiencing chronic sorrow, (b) assuming responsibility for glucose highs and lows, (c) managing T1D and nighttime sleep disturbances, (d) making career sacrifices and choices to optimize T1D care, (e) navigating social experiences postdiagnosis, and (f) discovering new sources of support through online platforms. **Conclusions:** This synthesis highlights an all-encompassing experience involved in caretaking for a child with T1D. Caregiving duties lead to a constant sense of vigilance, especially due to fear of hypoglycemic incidents. Parents commonly experience challenges with balancing work demands with T1D management, which lead to career and financial sacrifices. Their burden of care is exacerbated by a lack of reliable respite care but helped somewhat by online peer support. Future research is needed on the care burden differences between mothers and fathers and how sociodemographic factors affect how caregiver burden is experienced.

Keywords: Diabetes mellitus type one, parents, caregiver burden, burnout, child, glucose

Caregiver Burden Among Parents of Children With Type 1 Diabetes: A Qualitative Scoping Review

Type 1 diabetes (T1D), formally known as insulin-dependent, juvenile, or childhood-onset diabetes, is the most common incurable endocrine disorder among children and is on the rise globally (Rankin et al., 2016). T1D is estimated to account for 10% of all diabetes cases, with incidence rates increasing by 3%–4% yearly (Hex et al., 2012; Norris et al., 2020; Saeedi et al., 2019). The interplay among several environmental and genetic factors and exposure trajectories have been linked to the onset of T1D, with no conclusive explanation for its cause (Norris et al., 2020). In T1D, the pancreas produces little or no insulin, a glucose-regulating hormone, due to the destruction of insulin-producing B cells (Norris et al., 2020). The associated health complications and long-term health risks can be severe, including kidney failure, cardiovascular disease, retinopathy, hypoglycemia (glucose that falls and stays below a safe range), limb amputations, and neuropathy (Atkinson et al., 2014).

Given that T1D is diagnosed at a young age, children are significantly dependent on their parents for the management and care of their diabetes (Feeley et al., 2019). In addition to the normative tasks of supporting the cognitive, physical, and emotional growth of their children, parents of children with T1D are required to consistently monitor and regulate diet and exercise, utilize technologies such as a glucometer or insulin pump, or administer daily insulin injections, and prevent hypoglycemia episodes (Pierce et al., 2017; Smaldone & Ritholz, 2011). The responsibilities involved in managing T1D in children can be taxing for a caregiver (Sullivan-Bolyai et al., 2003). Any error in daily management can lead to an acute event, so constant daily treatment, vigilance, and management are required to reduce the risk of complications (Rechenberg et al., 2017). As a result, the imbalance of time and demand between caretaking and other required responsibilities and roles can result in caregiver burden (Adib-Hajbaghery & Ahmadi, 2019). Caregiver burden refers to the financial, physical, social, spiritual, and emotional or psychological problems experienced by family members caring for a chronically ill loved one (Chou, 2000; Toledano-Toledano & Domínguez-Guedea, 2019).

Although some reviews of quantitative evidence have aimed to understand the psychological impacts of caregiving for a child with a chronic condition, including T1D (Whittemore et al., 2012), no qualitative review has specifically explored the multifaceted dimensions of the caregiver burden among parents of children with T1D. One recent qualitative systematic review by Kimbell et al. (2021) aimed to fill this knowledge gap; however, they confined their review to the experiences of parents of children with T1D under the age of 8, limited their search to studies published in 2002 and onwards, and did not specifically aim to explore the concept of caregiver burden.

Therefore, we conducted a qualitative scoping review to describe the breadth of experiences and perspectives of caregiver burden, as defined by Chou (2000), among parents. That is, we used the dimensions of financial, physical, social, spiritual, and emotional or psychological stressors as a guiding framework to explore the underlying attributes and consequences of caregiver burden in parents of children with T1D. This review is also unique in that it was not confined to reviewing the experiences of parents of children of a particular age group. We aimed to capture what is known about caregiver burden among parents of children of any age with T1D. Understanding the caregiver burden experience of parents of children with T1D may provide direction on how best to alleviate some of the burden of care. Research has indicated that enhanced support for caregivers also translates to better caregiving, diabetes management, and health outcomes in their affected children (Anderson & White, 2018; Rechenberg et al., 2017).

Methods

Scoping reviews are commonly conducted to explore the nature and scope of research on a topic (Arksey & O'Malley, 2005). By systematically "mapping" the literature, scoping reviews provide readers with an overview of existing literature to identify areas where further research may be required (Arksey & O'Malley, 2005). As such, this qualitative scoping review aimed to (a) describe and understand the published evidence base on parental caregiver burden for children with T1D and (b) identify gaps in the existing literature and highlight implications for future research. We conducted the review process using the five stages of Arksey and O'Malley's (2005) methodological framework: (a) identifying the research question; (b) searching for relevant studies; (c) selecting relevant studies; (d) collecting, charting, analyzing, and summarizing the data; and (e) summarizing the results.

Stage 1: Identifying the Research Question

The research question that guided this review was: What is the experience of caregiver burden among parents of children with T1D?

Stage 2: Identifying Relevant Studies

The scoping review search strategy aimed to find articles describing the experiences of social, physical, emotional, psychological, and spiritual burdens among parents caring for children with T1D. To identify relevant studies, a list of search terms was first developed in consultation with an expert health sciences librarian (SC) and by reading through the literature. Keyword sets were established through an iterative process of testing and refining words and search concepts. SC then executed a search using controlled vocabulary (e.g., MeSH, Emtree) and keywords representing the concepts “caregivers,” “burden,” “type 1 diabetes,” and “qualitative studies” on the following databases: PsycINFO, PROSPERO, OVID Medline, OVID EMBASE, Cochrane Library (CDSR and Central), EBSCO CINAHL, ProQuest Dissertations and Theses Global, and SCOPUS. To ensure comprehensiveness, databases were searched from inception to December 2022, and we did not limit our search to published reports only. We also searched the grey literature using the search string “T1D” AND “caregiving burden” AND “parents” on Google (in January 2023). The first 25 results were screened and reviewed; however, no data from these search results was found relevant or included in our study. The full search strategy for each database and inclusion PRISMA-S checklist can be found in the supplementary materials at https://doi.org/10.1016/j.heliyon.2024.e27539.

Adult-only and quantitative studies were excluded. No other limits were applied. A total of 1,952 citations were exported to COVIDENCE, a review management software. Duplicates (388) were removed, leaving 1,564 search results to review for inclusion and exclusion, and 119 full-text articles to review for analysis. Of the 119 full-text articles that were selected for review, 18 were included in this scoping review (see Appendix 2A for a summary of the data).

Stage 3: Selecting Relevant Studies

Once duplicates were removed, each result was independently screened and reviewed first by title and abstract and then by full-text review by the research lead (TA) and a research assistant (ST). As an additional review measure, reference lists of included studies were also manually reviewed to ensure no relevant articles had been missed. No additional relevant articles were identified through this search. Non-peer-reviewed sources that were exported to Covidence from our search strategy were screened but not selected for full-text review as these search results did not address our research question. TA and ST independently conducted the quality appraisal using the Critical Appraisal Skills Programme for qualitative research (CASP; see https://casp-uk.net/) for studies in full-text review. Any conflicts over inclusion of studies during any stage of the screening and review process were carefully considered, discussed between TA and ST, and resolved. A third individual (SM) provided input and guidance when a decision could not be made.

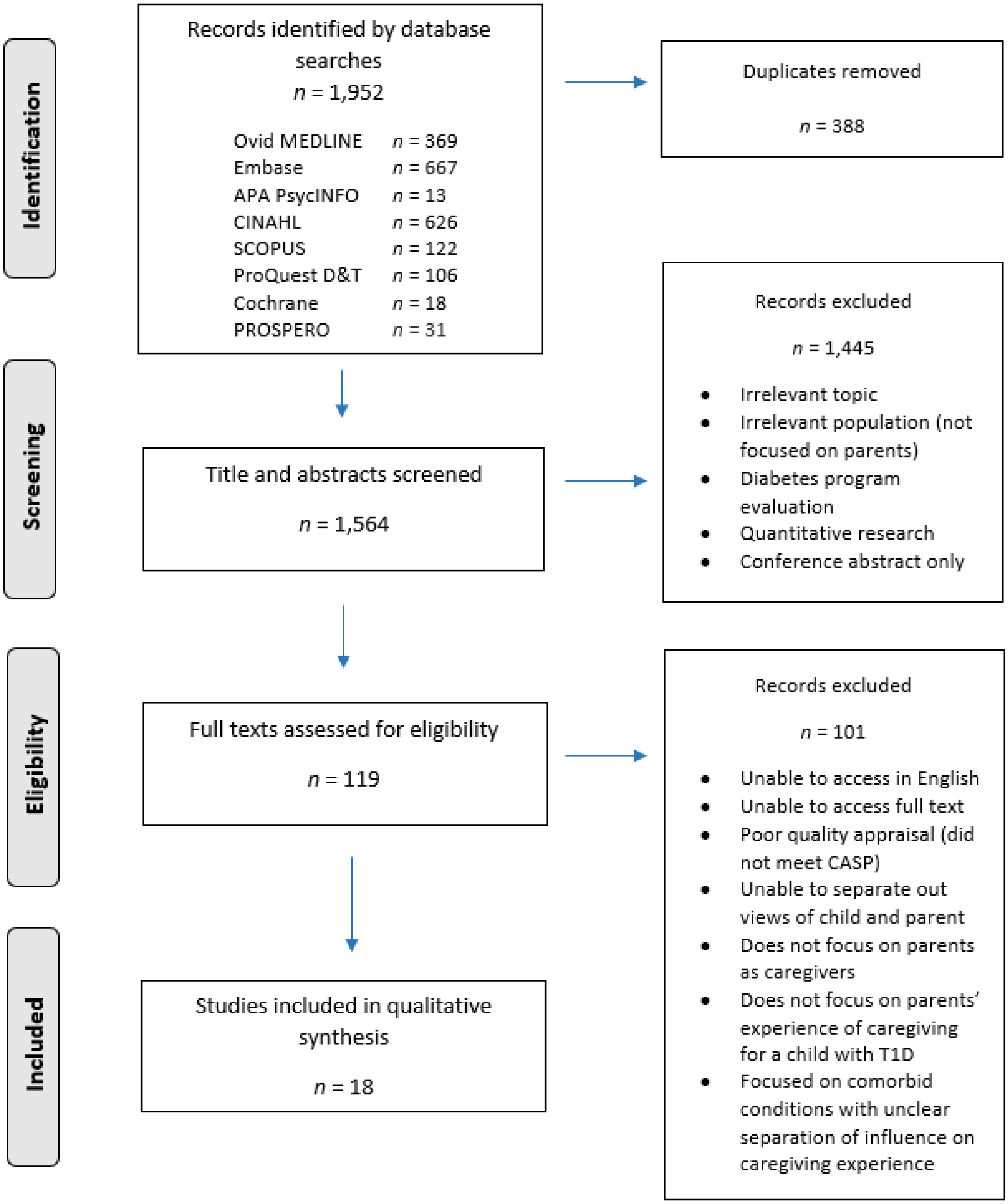
Peer-reviewed qualitative studies were considered relevant if they specifically focused on diabetes management and burden among parents or the day-to-day experience of caregiving for a child with T1D. More specifically, articles were included if they had a discussion of psychological, emotional, social, financial, physical, and or spiritual experiences of parents of children with T1D. Studies that focused on diabetes technology, diabetes program evaluation, or the experiences of those who were not parental caregivers, such as medical professionals or school staff, were excluded. Research articles or studies involving interviews of parent–child dyads that did not clearly differentiate between the parent's and child's experiences in the findings were omitted. Finally, we did not include studies that were not translated into or accessible in English. This process left 18 papers for inclusion in data extraction (see Figure 2.1).

Stage 4: Charting and Synthesizing the Data

Scoping reviews involve a practice of charting the existing literature or evidence base (Arksey & O'Malley, 2005). We created a comprehensive charting table in Microsoft Excel to extract data from the literature selected for this review synthesis to answer the research question. The extraction table was developed by TA and reviewed by SM to ensure breadth. Data were first extracted to summarize study characteristics such as study descriptors, study aims, methods, and geographical location where the study was conducted. Then, we charted the goal of each paper, the main findings, included themes and subthemes, the gendered experience of caregiving, study implications, and noteworthy quotes and findings related to financial, spiritual, physical, social, emotional, and psychological stressors for each study.

Figure 2.1

Prisma Diagram, Search Results, and Article Selection



TA and ST independently extracted data for each full-text article and compared and combined those data. A pilot of the extraction was first conducted to ensure each person was recording similar data. During the data extraction process, additional charting sections were added to the table if deemed essential or initially overlooked. All changes to the process and charting table were documented. To confirm that no information was missed, all articles were re-read and extracted once again if a new section of inquiry was added to the table.

Following Maxwell's (2005) and Miles and Huberman's (1994) qualitative techniques, TA and ST analyzed the extracted and charted data using thematic analysis. The data were open coded and reviewed for patterns, similarities, and differences. This was done within and across the charted domains of social, financial, physical, emotional, psychological, and spiritual experience to identify emerging themes. Disagreements in data analysis were resolved through discussion and data review until both researchers reached a consensus.

Results

This scoping review explored the existing literature on the experiences of caregiver burden among parents caring for children with T1D. Of the 18 studies included in this review, two studies recruited only mothers as participants whereas the remainder recruited both fathers and mothers as participants. Mothers represented a larger percentage of the participants compared to fathers in these studies.

Six interrelated themes were identified and are described in detail below: (a) experiencing chronic sorrow, (b) assuming responsibility for glucose highs and lows, (c) managing T1D and nighttime sleep disturbances, (d) making career sacrifices and choices to optimize T1D care, (e) navigating social experiences postdiagnosis, and (f) discovering new sources of support through online platforms.

Theme 1: Experiencing Chronic Sorrow

Across all studies, parents described the initial sense of shock, anxiety, guilt, and despair they experienced when their child was first diagnosed with T1D. Parents expressed feeling overwhelmed and filled with sadness and self-doubt as they adjusted to diabetes care (Smaldone et al., 2011). One parent explained: “I felt like my old kid was taken away and now I had this new kid that I didn’t know how to take care of. I didn’t even know how to go about it” (Smaldone et al., 2011, p. 90). However, although this normative initial state of shock and anxiety lessened over time, we found that a sense of grief and loss lingered; some parents described that it even intensified at times. Parents expressed concern over the complex life their children would have to endure and described a sense of loss (Lindström et al., 2017). They discussed grieving for their child’s inability to indulge in food without repercussions, the loss of spontaneity and freedom for them and their children, a life of monitoring glucose numbers and fearing health outcomes, and, commonly, the loss of a previously healthy child (Sullivan-Bolyai et al., 2003; Symons et al., 2015).

Findings from the studies we reviewed indicated that feelings of grief and loss were common irrespective of the amount of time that had passed since diagnosis (Abdoli et al., 2020; Bowes et al., 2009; Symons et al., 2015). One mother in a study by Abdoli et al. (2020), for instance, shared: “I think it's a never-ending process with grief. You cry for a life that you never had or a life that you missed. You cry for a good night's sleep. . . . I miss having a life of my own” (p .4). Even if parents’ feelings of despair were not as intense as the initial period postdiagnosis, such feelings could easily resurface (Abdoli et al., 2020). One parent explained: “As time goes by, there is not the same drama about the whole thing, but I still feel the despair and the loneliness when I let it come to me” (Iversen et al., 2018, p. 4). In fact, when assessing long-term experiences in parents specifically, Bowes et al. (2009) found that although parents adapted to the needs of T1D management, their experience of resurgent grief was common even 7 to 10 years after diagnosis.

Theme 2: Assuming Responsibility for Glucose Highs and Lows

A major psychological and emotional burden experienced by parents caring for children with T1D is anxiety related to maintaining glucose levels within ideal or clinically recommended ranges. Parents have emphasized the importance, responsibility, and pressure of sustaining near-normal glycemic control to optimize their child's quality of life and health outcomes (Abdoli et al., 2020; Commissariat et al., 2020; Symons et al., 2015). Higher glucose levels are unequivocally and exponentially linked to the risk of diabetes-related complications (Diabetes Control and Complications Trial Research Group, 1993). As such, many parents have identified a sense of powerlessness, failure, fear, and guilt associated with the inability to maintain their children's glucose within the recommended or ideal range. In a qualitative descriptive study Abdoli et al. (2020) conducted, one parent shared:

> It's kind of a guessing game. I know it's based on math, but diabetes doesn't always listen to math. No matter how hard we try, diabetes is gonna sometimes just throw us a curve ball. I am trying to do my best for his [my son's] diabetes, but I can't. I can't keep it on track, which is very frustrating. It is scary to think "I'm causing serious damage to my son's body." (p. 4)

Parents commonly discussed various unexpected and unanticipated factors that influenced their child's fluctuating blood glucose levels. And, because of the unpredictable nature of T1D and the importance of maintaining healthy glucose levels, diabetes care was greatly associated with a perpetual state of vigilance, food intake monitoring, and parents having to take precautions (Abdoli et al., 2020; Feeley et al., 2019; Iversen et al., 2019; Lindström et al., 2017; Rifshana et al., 2017; Symons et al., 2015). Parents interviewed across several studies echoed one another's sentiments, with comments such as "I worry about his blood sugar number all the time" (Feeley et al., 2019, p. 82), and "You must be focused at all times. You must be focused on what you do; you must be able to plan. Therefore, you must always be ahead of the game and continuously plan" (Lindström et al., 2017, p. 152). In fact, parents anticipated not ever being unconcerned about their child's glucose levels. As father of a 10-year-old girl expressed, "I see it as a lifelong role, myself. Even when she's married, I'll be phoning up saying, 'What's your BM [blood sugar level]?' I really believe that's what I'll be like" (Lowes et al., 2005, p. 256).

Caregivers have also emphasized an associated sense of self-doubt and anxiety with managing glucose levels as they have had to make daily and emergency decisions related to glucose adjustments. This type of anxiety was mainly described by mothers, as compared to fathers, given that mothers were represented as being the primary caregiver or decision-maker in the majority of the studies included in this scoping review. For instance, one mother shared: "The first time I wanted to inject insulin, my hands were shaking. I was so upset and scared that I could not do it, so I asked my brother to inject the insulin" (Khandan et al., 2018, p. 80).

Self-doubt with one's ability to manage glucose highs and lows was especially a concern during the early days postdiagnosis and often improved over time (Iversen et al., 2018; Khandan et al., 2018). Even so, stress with management of appropriate glucose levels and overall fear of deadly consequences remained a constant in the lives of caregivers (Feeley et al., 2019; Iversen et al., 2018; Khandan et al., 2018; Oser et al., 2017). Fears were intensified among parents of younger children with T1D because younger children are less capable of identifying and communicating their physical symptoms to their parents (Commissariat et al., 2020; Iversen et al., 2018). Findings from several studies emphasize the importance of health care providers offering more direction and reassurance after diagnosis. Knowledge and mastery of skills required to manage T1D, especially soon after diagnosis, can improve parents’ ability to cope, raise their sense of empowerment, reduce their perception of stress, and thus mitigate caregiver burden (Meleski, 2002; Pierce et al., 2017). In fact, clear home management directions and consistent follow-ups have been shown to enable parents to effectively integrate diabetes management into a family’s lifestyle and improve control over glucose highs and lows (Commissariat et al., 2020).

Theme 3: Managing T1D and Nighttime Sleep Disturbances

Findings from the literature consistently indicate that sleep deprivation due to nighttime caregiving is a common burden among parents of children with T1D. This is often due to being woken by alarms from diabetes management devices and doing multiple glucose checks throughout the night (Abdoli et al., 2020; Feeley et al., 2019; Iversen et al., 2018; Lindström et al., 2017; Macaulay et al., 2020). Hypoglycemia or severely low blood sugar is the greatest feared outcome among parents during nighttime diabetes care, resulting in repeated nocturnal glucose monitoring (Commissariat et al., 2020; Feeley et al., 2019; Iversen et al., 2018; Macaulay et al., 2020). Parents commonly report that this fear leads to a lack of sleep, stress, exhaustion, and anxious or interrupted sleeping patterns. For example, in a qualitative study of caregiver blogs that Oser et al. (2017) conducted, one mother shared:

> How do I explain to you that some nights the exhaustion holds me like a straight jacket, . . . that the nights are all encompassing, and I will hold my tears to fall back into my body rather than intentionally give in to the fear and exhaustion? (p. 4)

Other parents shared similar sentiments: “I just don’t get a full night’s sleep, ever. I just feel like I’m constantly tired” (Macaulay et al., 2020, p. 630); “I test her [my daughter’s] blood sugar every 2 hours between 10 pm and 6 am in an attempt to catch any fluctuations that might require an intervention” (Lindström et al., 2017, p. 5); and “I am the mother of a 12-year-old diabetic child. I don’t know what it’s like to go to sleep at night and know for certain [my] child will wake up in the morning” (Abdoli et al., 2020, p. 4).

Challenged with balancing adequate sleep and their need for wanting to know frequently what their child’s blood glucose levels were during the night, parental caregiver participants in many studies described the negative impacts sleep deprivation had on their emotional and physical well-being (Feeley et al., 2019; Macaulay et al., 2020., Sullivan-Bolyai et al., 2003). A mother of a six-year-old boy explained:

> I feel unhappy when I think about not sleeping, feeling anxious and feeling tired and moody all the time. So, it’s rather contradictory because I am obviously satisfied that things are well and that [my child] feels fine. . . . At the same time, I may not feel satisfied because I do not feel well, really. (Lindström et al., 2017, p. 154)

Fatigue and sleep disturbance were noted to result in short tempers, reduced ability to exercise and make decisions, delayed work performance, poor dietary choices, decreased patience, and irritability. Some study participants expressed that sleep deprivation also led to reduced relationship satisfaction and worsened their home environment (Feeley et al., 2019; Macaulay et al., 2020). For instance, one participant explained:

> I’m finding, you know, particularly when there’s a marked difference between when we’ve had quite a bit of sleep and when we haven’t had any sleep, in the way that we all interact with each other and the happiness that flows around the house. (Macaulay et al., 2020, p. 630)

Findings from various studies indicate that caregiver sleep disruption continues irrespective of the child’s age and development (Macaulay et al., 2020; Sullivan-Bolyai et al., 2003).

Theme 4: Making Career Sacrifices and Choices to Optimize T1D Care

Contemplating alternative career choices is a common part of T1D care for many parents. Due to the constant need to monitor and manage their children’s health needs, most parents of children with T1D have reported experiencing some form of impact on their careers postdiagnosis. For many parents, the burden of care results in decisions to adjust work hours, not pursue higher career ambitions due to the potential work demands involved, and avoid desired job opportunities without adequate diabetes health benefit packages (Eshtehardi et al., 2021; Khandan et al., 2018; Tong et al., 2022). For instance, describing her career ambitions postdiagnosis, one mother in Tong et al.'s (2022) study involving parental caregivers of children with T1D in China shared:

> Now I rarely focus my energy on the company [I work for]; I just get off work as soon as possible. I used to leave early and return late to make money. Now I quit my job and found a new one that can make a living while taking care of my child. (p. 5)

In our review, we also found career-related decisions to be influenced by the economic burden that T1D imposes on families. For example, parents expressed financial stresses, such as "The test strip and the insulin needle are too expensive. We did not have such costs earlier; we have to save by cutting down on family expenses for the sake of our child" (Khandan et al., 2018, p. 82). To alleviate the financial burden involved in T1D care and to meet the high costs of treatment, some parents have contemplated how to work longer hours and sought to find higher-paying jobs, especially if they did not have extended health benefits (Khandan et al., 2018; Perez et al., 2019).

Balancing new health costs with the demanding care involved in managing T1D has led to various employment decisions and stressors among parents. However, given that women take responsibility for most of a child's caregiving needs, including for children with T1D (Hatton et al., 1995; Keklik et al., 2020), sacrificing and modifying career commitments were more commonly discussed among mothers than fathers in the literature we reviewed.

Theme 5: Navigating Social Experiences Postdiagnosis

Learning to navigate social experiences was another situation parents of children with T1D commonly found themselves in postdiagnosis. Many parents struggled with attending social gatherings due to the disruptiveness and seriousness of their child's disease. They found it difficult to be present and not concentrated on monitoring their child's potential glucose fluctuations or dietary choices. For instance, one parent explained:

> It is inevitable that [when living with a child with T1D] you can't be the same as other families. We have to consider our child's physical strength and whether [he] can eat regularly. Especially when faced with a table full of good food, it is uncomfortable for the child to see others eating. (Tong et al., 2022, p. 5)

Other parents shared that postdiagnosis, they avoided taking vacations and attending outings and social events altogether. One said, "There's just so much to do for our infant. The management consumes our lives. There is no time to socialize, no time even for each other" (Hatton et al., 1995, p. 574). Another stated, "Since my child had a ketosis coma, I have never dared to relax again. I have lost myself. Every day in the year, there are no more visits to relatives or friends" (Tong et al., 2022, p. 5).

Even when parents longed for social connection with others, or alone time for self-care practices, and they strived to plan date nights, events, and getaways without their children present, they experienced challenges with finding reliable formal and informal supports for respite care. Once parents had overcome the hurdle of needing to trust others to manage their child's complex health needs, they then found that caretakers and family members were reluctant to care for the child in the parents' absence (Khandan et al., 2018; Smaldone & Ritholz, 2011; Sullivan-Bolyai et al., 2003). Extended family members, friends, and formal supports either refused to babysit, were not skilled in diabetes management, or were unwilling to learn how to care for a child with T1D. A mother of a 3-year-old boy explained: "No [secondary] caregivers felt comfortable. . . . None of the babysitters that we were interviewing felt comfortable giving an insulin shot with a syringe" (Commissariat et al., 2020, p. 380). Another mother from a different study similarly said, "Nobody is willing to accept him for a day. They say they are afraid. If his blood sugar goes up or down, they cannot calculate his insulin unit" (Khandan et al., 2018, p. 80).

Parents also expressed that there was a lack of knowledgeable formal respite supports available to them, such as caregivers and care aids who knew how to manage T1D. A lack of social supports and thus reduced opportunities to socialize have been found to negatively impact parent caregivers' mental health and well-being. Parents have shared feeling more depressed, stressed, and isolated because of the restrictions they have on socializing, joining recreational activities, and spontaneously attending events since their child's T1D diagnosis (Hatton et al., 1995; Pierce et al., 2017; Sullivan-Bolyai et al., 2003).

Theme 6: Discovering New Sources of Support Through Online Platforms

Parents of children with T1D have commonly expressed feeling stigmatized and misunderstood by their extended family members and by parents whose children do not have T1D. The responsibility of care involved with T1D is often unrecognized and underestimated, leaving them feeling unsupported and lonely (Symons et al., 2015). For instance, in a phenomenological study of parents' caregiving experience by Rifshana et al. (2017), one participant stated:

> I don't think people truly understand how hard it is on us on a physical, daily, everyday thing. People don't get it. And I think because we are coping and we're fine, people just think oh it must be fine. But it's really hard, and they don't get that. They don't get that, um, whereas if your child had cancer, people'd drop off meals and people would be running round after you, thinking oh you poor things it's terrible, but they're like oh no it's fine. (p. 3233)

Although medical staff and diabetes teams were considered important sources of support, parents felt that they too did not fully understand the struggle of caring for a child with T1D and were not always available to immediately answer questions or discuss concerns that arose unexpectedly (Perez et al., 2019). As a result of this sensed lack of understanding, many caregivers highlighted the importance of finding new supports, friendships, and comfort in connecting with other parents of children with T1D, also referred to as peer support. Peer support "involves learning and information exchange in interaction with people in similar situations" (Boman, 2018, p. 1176). In the T1D community, peer support was often found through online networks such as blogs, Facebook groups, and online forums.

The quality and availability of support and understanding from other parents of children with T1D alleviated stress and loneliness among caregivers and created an opportunity to ask questions and discuss how to navigate diabetes care. Parents of children with T1D expressed the benefits peer support had in their lives as caregivers through sentiments such as, "The only time you don't feel lonely is when you have that bond with others in the type 1 community" (Perez et al., 2019, p. 6), and "I found the [parenting children with T1D] blog early in our journey and it gave me so much more than you will ever know" (Oser et al., 2017, p. 5). Another parent noted, "We've shared everything right from the beginning. . . . It's nice to have someone else to bounce this off of. I'm like, he's been high here, here, here, and here. What do you think? And we figured it out" (Smaldone & Ritholz, 2011, p. 90).

Discussion

This qualitative scoping review aimed to synthesize and describe caregiver burden, which we defined as financial, physical, social, spiritual, and emotional or psychological stressors among parents of children with T1D (Chou, 2000; Toledano-Toledano & Domínguez-Guedea, 2019). This synthesis highlights, through the identification of six interrelated themes, constant and all-encompassing experiences involved in caretaking for a child living with T1D. We first discuss these themes and their interrelationships. We then revisit the gaps in the research and suggest ideas for future inquiries before sharing our conclusions.

Parents experience an initial period of sadness, shock, and overwhelm after their child is diagnosed with T1D, but they must quickly adapt to a new normal. New routines are established to accommodate care needs, and all life decisions are made with prioritizing T1D management in mind. For instance, we found career choices to be a common factor that parents had to reassess. Hours spent at work were either reduced to accommodate demanding and routine-based management needs or increased to accommodate the high costs associated with care (Eshtehardi et al., 2021; Khandan et al., 2018; Tong et al., 2022). Diabetes-related costs were particularly concerning when parents did not have health insurance or adequate coverage for diabetes supplies. In the studies we reviewed, female participants interviewed were more expressive about needing to reconsider, restrict, or modify their employment situations compared to their male counterparts.

As part of their new normal, parents partake in constant monitoring of glucose highs and lows to achieve healthy and ideal glucose levels for their child. Numbers outside of an ideal glucose range are often accompanied by a strong sense of guilt, shame, anxiety, and concern for negative future health outcomes. These emotions lead to a constant sense of vigilance and calculated planning during T1D care, creating a more restrictive lifestyle for parents, thereby limiting time for self-care, reducing opportunities for social activities, and worsening experiences of poor mental health (Abdoli et al., 2020; Iversen et al., 2018; Lindström et al., 2017; Rifshana et al., 2017; Symons et al., 2015; Tong et al., 2022). These negative emotions and their repercussions are exacerbated by lingering feeling of sadness and grief that persist even years after the initial diagnosis. Parents lament the loss of the typical life experiences their healthy child would have had and grieve for the difficult life their child will undergo.

Although daytime T1D glucose management has its own challenges, we found concern over unstable glucose numbers, especially fear of hypoglycemic incidents, to be exceptionally worrisome during nighttime diabetes monitoring. This finding also appeared in Kimbell et al.'s (2021) systematic review. This fear and the related need to complete frequent nighttime checks often results in unrestful and reduced sleep, leading to disruptions in mood for both parent and child, conflict between married couples, and even physical implications such as headaches. Given that mothers reported being mostly responsible for nighttime caregiving duties, they relatedly also expressed more sleep deprivation compared to fathers (Commissariat et al., 2020; Feeley et al., 2019; Iversen et al., 2018; Macaulay et al., 2020; Sullivan-Bolyai et al., 2003).

Our findings suggest that the burden of care experienced by parents of children with T1D is influenced not only by the unique requirements of T1D management but also by the parents' perception of social support received. Family and friends' lack of understanding and willingness to learn about T1D was a common complaint for parents. This dearth of support results in parents having reduced access to respite care from extended family members and concerns with entrusting others to capably manage their child's diabetes. In addition to a lack of respite care from informal supports, parents stated that paid formal supports, such as babysitters skilled with T1D training, were equally difficult to find (Khandan et al., 2018; Rankin et al., 2016; Smaldone & Ritholz, 2011; Sullivan-Bolyai et al., 2003).

A lack of available and reliable respite care made it challenging for parents to partake in the types of activities they enjoyed prior to their child's T1D diagnosis: travelling, investing in longer hours at work, having date nights, participating in social activities, or generally having time away from T1D care duties. For many parents, this was not simply a new normal they needed to accept, but rather an aspect of their lives they missed and associated with a sense of loss (Hatton et al., 1995; Pierce et al., 2017; Sullivan-Bolyai et al., 2003). Lacking respite care also resulted in attending social settings with new challenges that parents had to navigate and manage. Parents expressed that they were unable to escape their sense of vigilance and their obligations to monitor their children during outings, disrupting their enjoyment (Tong et al., 2022). These findings emphasize the importance of access to respite care and the need to train and equip professionals or extended family members with the skills to offer safe and reliable respite relief to parents. Such assistance may improve the mental health of parents and support their ongoing ability to care for their children's T1D needs.

Our findings demonstrate that parents of children with T1D undeniably face many novel experiences and challenges. They must consider alternative ways of navigating through work–life balance, social activities, and daily and nighttime routines in order to provide optimal care for their children. However, we also found that parents were resourceful and sought assistance elsewhere when they felt unsupported by their family members or health care professionals (Rifshana et al., 2017). More specifically, they found comfort, relief, and practical support in connecting with other parents of children with T1D. An online diabetes community has emerged that uses forums, Facebook group pages, and blogs as popular platforms for peer support. Through these interactions, parents receive benefits such as finding social connection and emotional support, having opportunities to discuss technology and device use, learning about and sharing medical information, and sharing personal stories, successes, and challenges. This online peer support has been an important support system that parents of children with T1D have used to offset any absence of support they have felt by others (Oser et al., 2017; Perez et al., 2019; Smaldone & Ritholz, 2011).

Our six common themes exemplify the financial, physical, social, and emotional or psychological stressors in the definition of caregiver burden we chose (see the next section for a discussion of the spiritual dimension). Although some of our themes may align more with one stress domain compared to another, it is important to recognize that these stressors overlap. For instance, even though the theme of making career sacrifices and choices to optimize T1D care falls more within the realm of financial stressors, career sacrifices and changes can arguably have emotional and psychological impacts and thus also be considered an emotional stressor. This line of thought suggests that improving or alleviating stress from one area of a parent's life could have positive outcomes in one or more other areas. In fact, some research has even identified the positive impact that reduced burden of care on parents may have on the health of the child with T1D, such as more stable glucose numbers (Anderson & White, 2018; Rechenberg et al., 2017). Stable glucose numbers may then have a domino effect, whereby that improved health outcome reduces the parents' anxiety and fear.

Research Gaps and Implications for Future Research

Kimbell et al. (2021) conducted a recent systematic review that aimed to fill a similar research gap as this review paper. Their study parameters were different, but they echoed similar findings. This overlap in findings, we argue, strengthens the results of both studies. Overall, they highlighted the impacts of psychological, physical, and financial stressors on parents caring for children with T1D. First, they noted the stress related to the perpetual state of hypervigilance needed to manage glucose levels, especially during the night. Second, they found that parents had difficulty with finding reliable respite care and entrusting others with their child. They termed these experiences as 'monopolization of life. As our study inclusion criteria were not limited to caregiving for children under a particular age group, our findings add to the literature and exemplify that caregiver burden remains continuous in the lives of parents.

These intersecting findings notwithstanding, large gaps remain in the literature on T1D and parental caregiver burden. For instance, in our review, we found no data on the role or impact of spirituality, nor was it included in any of the research questions of any studies. Additionally, even though social and financial stressors were documented across study findings and resulted in common themes for this synthesis, we did not find any articles that specifically explored these domains of life in depth. Given the financial and social burdens a T1D diagnosis creates, specific research dedicated to these aspects is warranted.

Likewise, we found minimal discussion on the specific care burden differences between fathers and mothers. This gap is noteworthy given that mothers were consistently identified as primary caregivers and noted to take on more care management tasks compared to fathers. Understanding how mothers and fathers uniquely experience their caregiver roles and caregiver burden would allow health professionals to identify how to alleviate stressors and provide support that is more tailored. One reason for the limited discussion on this topic may be because fathers represented a smaller percentage of the participants in the research studies compared to mothers, thereby stipulating less gender-based information.

Furthermore, whereas we discovered consistency of findings across the studies, the majority were conducted in the United States or Europe and recruited predominantly White participants. Only two of the studies we extracted data from were conducted elsewhere: one in China and one in Iran. A limitation of this synthesis was that we included only articles published in English. We may have missed important information published in different languages. Additionally, the majority of the participants in the studies we reviewed were married, cohabitating with their partner, and employed. As such, the experiences presented in this synthesis may not be reflective of parents who are unemployed, single, or from a different racial or cultural background. Future research would benefit from considering the impacts of different socioeconomic and demographic backgrounds as they relate to caregiver burden. More nuanced findings and details about participant data may help health professionals and policy decision-makers offer more customized supports and solutions to aid parents of children with T1D.

Conclusions

This qualitative scoping review is the first to explore the concept of caregiver burden among parents of children with T1D. The current literature emphasizes themes of persistent financial, physical, social, and emotional or psychological stress that stems from caring for a child diagnosed with T1D. The importance of respite care and social support in alleviating these stressors and aiding parents in their role as caregivers are also discussed. Future research would benefit from exploring if and how mothers and fathers experience caregiver burden differently and the role of sociodemographic factors in how caregiver burden is experienced. Studies dedicated to explicitly exploring the domains of financial, physical, social, spiritual, and emotional or psychological stress would also be useful. Such research findings may instigate the development and provision of nuanced and tailored supports.

Chapter 2 References

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Appendix 2A: Summary of Data From Included Studies

Author and year	Title	Setting	Data collection sources	Sample	Study findings
Abdoli et al., 2020	I Don't Have the Choice to Burnout: Experiences of Parents of Children With Type 1 Diabetes	Eight videos produced in the United States, six in the United Kingdom, one in Canada, and six in unknown countries	21 video blogs	21 parents	Parental burnout is related to exhaustion resulting from the daily demands of diabetes care (e.g., self-care behaviors, insurance, and pharmacy), feeling powerless to attain diabetes care goals consistently, and loss of a previous way of life.
Commissariat et al., 2020	"I'm Essentially His Pancreas": Parent Perceptions of Diabetes Burden and Opportunities to Reduce Burden in the Care of Children < 8 Years Old With Type 1 Diabetes	United States	Semi-structured interviews	79 parents or legal guardians	Parents struggled with the (a) emotional burden of diabetes on themselves and their children; (b) burden of finding, training, and trusting effective secondary caregivers; and (c) need for more comprehensive diabetes education from health care providers that could help reduce their burden.
Bowes et al., 2009	Chronic Sorrow: Periodic Resurgence of Grief in Parents of Children With Type 1 Diabetes Seven to Ten Years After Diagnosis	United Kingdom	Semi-structured interviews	17 parents	Parents, especially mothers, experienced grief and despair even 7–10 years after their child's diagnosis.

Author and year	Title	Setting	Data collection sources	Sample	Study findings
Eshtehardi et al., 2021	On the Money: Parental Perspectives About Finances and Type 1 Diabetes in Youth	United States	Semi-structured interviews	20 parents	Parents of youth with T1D described experiencing financial hardships and making sacrifices in their spending or employment decisions to afford the costs of diabetes care.
Feely et al., 2019	Sleep in Caregivers of Children With Type 1 Diabetes	United States	Open-ended question-naire	22 parents	Caregivers are frequently sleep-deprived and experience anxiety about their child's nighttime glucose levels. Caregiving duties, anxiety, and sleep fragmentation contribute to the poor sleep in parents.
Hatton et al., 1995	Parents' Perceptions of Caring for an Infant or Toddler With Diabetes	Canada	Minimally structured interviews	Eight two-parent families	Stresses were experienced through three distinct phases: the child's diagnosis and hospitalization, adjusting to care at home, and long-term adaptation. Parents experienced recurring sadness, anger, anxiety, fear, and perceived loss of control throughout these phases.
Iversen et al., 2018	Being Mothers and Fathers of a Child With Type 1 Diabetes Aged 1 to 7 Years: A Phenomenological Study of Parents' Experiences	Norway	Semi-structured interviews	15 parents	Parents found the management of T1D to be life-changing, requiring constant care resulting in the establishment of new routines. They reported difficulty with constant worry and monitoring. Mothers expressed

Author and year	Title	Setting	Data collection sources	Sample	Study findings
					struggling more emotionally than fathers.
Khandan et al., 2018	Lived Experiences of Mothers With Diabetic Children From the Transfer of Caring Role	Iran	Semi-structured and open-ended interviews	11 mothers	Mothers felt constantly responsible for their child's glucose levels. They experienced financial and social challenges as a result of their child's care needs.
Lindström et al., 2017	"Mission Impossible": The Mothering of a Child With Type 1 Diabetes—From the Perspective of Mothers Experiencing Burnout	Sweden	Semi-structured interviews	21 mothers	Mothering a child with T1D involves an all-encompassing sense of responsibility and constant evaluation of mothering skills.
Lowes et al., 2005	Newly Diagnosed Childhood Diabetes: A Psychosocial Transition for Parents?	United Kingdom	Semi-structured interviews at 10 days, 4 months, and 12 months post-diagnosis	19 parents	Parents aim to adapt to a new lifestyle to meet the needs of their children with T1D. However, a T1D diagnosis continues to feel unpredictable, requiring constant revision and adaptation.
Macaulay et al., 2020	Sleep and Night-Time Caregiving in Parents of Children and Adolescents With Type 1 Diabetes Mellitus: A Qualitative Study	New Zealand	Semi-structured interviews	20 parents	Two periods are associated with an increased burden of care and greater sleep disturbance: immediately after their child's T1D diagnosis and the period of transitioning to using a new diabetes technology.

Author and year	Title	Setting	Data collection sources	Sample	Study findings
Oser et al., 2017	A Novel Approach to Identifying Barriers and Facilitators in Raising a Child With Type 1 Diabetes: Qualitative Analysis of Caregiver Blogs	United States	Blog posts	Three online blogs, consisting of 140 blog posts and 663 associated comments	Parents assume significant emotional and physical burdens in caring for their children with T1D. They face persistent fear and worry, especially surrounding hypoglycemia at nighttime. Consistent with previous findings, parents also expressed a sense of chronic sorrow with their child's condition. Parents find support through blog post discussions and connecting with other parents online.
Perez et al., 2019	Communicatively Exploring Uncertainty Management of Parents of Children With Type 1 Diabetes	United States	Interviews	29 parents	Three main forms of uncertainty surrounding their child's T1D diagnosis were reported: medical, social, and financial. Parents struggled with a lack of respite care and support from family and medical professionals; fears, frustrations, and doubts while adapting to diabetes care; and financial stress due to the cost of diabetes care.
Rifshana et al., 2017	The Parental Experience of Caring for a Child With Type 1 Diabetes	New Zealand	Semi-structured interviews	17 parents	The demands of T1D are ever-present, requiring ongoing conscious effort, active engagement, and attention, leading to a high degree of parental

Author and year	Title	Setting	Data collection sources	Sample	Study findings
					involvement and a lack of respite for the parents.
Smaldone & Ritholz, 2011	Perceptions of Parenting Children With Type 1 Diabetes Diagnosed in Early Childhood	United States	Open-ended interviews	14 parents	Experiencing inadequate direction and communication from health staff, feeling isolated and unsupported by others, and feeling overwhelmed with navigating diabetes care were major challenges for parents. Learning how to manage child developmental transitions with T1D was also a source of distress for parents.
Sullivan-Bolyai et al., 2003	Constant Vigilance: Mothers' Work Parenting Young Children With Type 1 Diabetes	United States	Semi-structured interviews	28 mothers	"Constant vigilance" was the primary behavior strategy mothers used for day-to-day management. The ongoing responsibility was compounded by the insecurity over whether one was providing adequate and vigilant care.
Symons et al., 2015	"The Whole Day Revolves Around It": Families' Experiences of Living With a Child With Type 1 Diabetes—A Descriptive Study	New Zealand	Semi-structured interviews	9 parents	Parents need to reappraise their lifestyle and adjust routines to accommodate dietary advice. Numerous T1D care management tasks need to be considered when day-to-day activities and social outings are being planned. Spontaneity disappears and families may become socially isolated if parents

Author and year	Title	Setting	Data collection sources	Sample	Study findings
					are uncomfortable leaving their child with T1D with others.
Tong et al., 2022	Characterising Common Challenges Faced by Parental Caregivers of Children With Type 1 Diabetes Mellitus in Mainland China: A Qualitative Study	China	Semi-structured interviews	20 parents	Parents experienced persistent psychological stress, changes to family function, challenges with daily management of glucose levels, changes in financial stability and career opportunities, and a lack of support from others.

Chapter 3: Exploring the Experiences of Mothers of Children With Type 1 Diabetes in Northern Alberta: A Qualitative Descriptive Study

The objective of this study was to understand the maternal experiences of caring for a child under the age of 18 with T1D in northern Alberta. My coauthors were Lisa Wozniak, Richard Oster, Jeffery Johnson, and Stephanie Montesanti. The manuscript was submitted for publication in April 2024 to *BMC Public Health*. To fit this dissertation, I have reduced major headings by one level, and I have included the chapter number in the table number. No other changes have been made to the original submission.

Chapter 3 Abstract

Objectives: Canada has one of the highest rates of Type 1 diabetes (T1D) in children. Management of their T1D and prevention of poor health outcomes often falls on mothers who are often the primary caregiver. The caregiving demands can result in substantial responsibility and stress. Mothers report career sacrifices, sleep deprivation, PTSD, grief, anxiety, and low mood. While globally Canada has a high rate of T1D, studies on the caregiving experience within a Canadian context have not been conducted. This study explored the experiences of mothers of children with T1D in northern Alberta, Canada. **Methods:** Utilizing a qualitative descriptive approach, we interviewed 16 mothers (average age = 37.1 ± 6) with children with T1D who were under the age of 18. We also drew upon a patient engagement in research approach to create a Caregiver Advisory Committee of three mothers of children with T1D. Advisory members collaborated with us and offered invaluable insight and feedback throughout the study. **Results:** Using thematic analysis, six themes were identified: (a) "I am the organ": a sense of constant vigilance, (b) accepting a new normal, (c) grief underlying a rollercoaster of emotions, (d) caregiving as an isolating experience, (e) the continuous glucose monitor (CGM) is a champion, and (f) finding the positives. Mothers face constant vigilance and anxiety, often feeling like their child's "organ" for survival. They view caregiving as an isolating experience with limited understanding and assumptions from people without children with T1D. Grief persists several years post diagnosis, intertwined with concerns and worries for the health and future of their children. New routines revolved around care taking duties result in the acceptance of lifestyle changes and shifts in priorities. **Conclusions:** Caring for a child with T1D presents many stressors for mothers. Over time, mothers gain confidence about their abilities as caregivers. They find relief in online T1D networks and access to CGMs, which alleviate some

anxiety and sleep deprivation but also present challenges. Our findings highlight the importance of improving access to affordable technology, psychological support and respite care to improve loss of personal time and constant vigilance.

Exploring the Experiences of Mothers of Children With Type 1 Diabetes in Northern Alberta: A Qualitative Descriptive Study

Type 1 diabetes (T1D) is an all-encompassing chronic condition that poses major challenges for those living with the condition. Canada ranks sixth among the top 10 nations in the incidence of T1D in children under the age of 15 (Patterson et al., 2014). Diagnosed mostly in children, the challenges affect both the child diagnosed and the caregivers involved in the child's care (Abdoli et al., 2020).

Management of T1D and prevention of poor health outcomes are described as a never-ending responsibility and a source of significant stress for parents as primary caregivers. Parents express feeling overwhelmed by the pervasive obligations of having to monitor glucose highs and lows; the constant fear of hypoglycemic events, especially during the night; and managing diabetes technology, all while still managing normative childhood growth and development (Commissariat et al., 2020; Feeley et al., 2019; Herbert et al., 2015). Parents also commonly describe apprehensions as their children begin attending school or are no longer in their constant care while transitioning towards independence and self-management of their T1D. Added to these challenges is myriad childhood developmental phases that raise new issues, requiring reevaluation of previously effective and established management strategies. As such, parents of children with T1D have been found to be vulnerable to psychological sequelae, anger, anxiety, depression, and ongoing worry (Bowes et al., 2009; Rechenberg et al., 2017).

Although only a few studies have compared the differences in caregiver experiences between fathers and mothers of children with T1D, in these studies, mothers are consistently recognized as the primary caregivers (Meleski, 2002; Wysocki & Gavin, 2006). Relatedly, mothers are said to be especially vulnerable to poorer health outcomes as they describe a higher perceived caregiver burden compared to fathers due to the amount of diabetes treatment they provide and the accompanying distress they experience (Herbert et al., 2015). In fact, mothers report performing 70% of all blood glucose checks and 79% of all insulin checks administered (Streisand & Monaghan, 2014; Sullivan-Bolyai et al., 2003). Findings by Rechenberg et al. (2017) suggest that anxiety levels in some mothers, not only during the first six weeks postdiagnosis but even five years afterward, meet the diagnostic criteria for posttraumatic stress disorder. Studies have shown that mothers of children with T1D also experience higher levels of anxiety and depression compared to mothers of healthy children or those with other chronic diseases (Streisand et al., 2005).

Complicating these psychological repercussions, mothers of children with T1D are particularly at risk of sleep deprivation and interrupted or poor-quality sleep compared to their male counterparts. This is a direct consequence of mothers taking on more nighttime diabetes management duties compared to fathers and experiencing fear of nighttime hypoglycemic episodes in their children (Feeley et al., 2019; Iversen et al., 2018). In addition to these findings, across several studies mothers have shared that they have had to make career sacrifices such as quitting their jobs or rearranging their work schedules to provide timely, consistent, and quality diabetes care to their children (Keklik et al., 2020; Pierce et al., 2017). For many mothers, leaving the workforce has led to both financial strain and reduced satisfaction with quality of life (Keklik et al., 2020).

As such, understanding the experiences of mothers of children with T1D is crucial, as this knowledge can help improve the well-being of both the mothers as caregivers and their children with T1D. Yet despite this significance and the need for exploration on this subject, few studies have been conducted specifically focusing on the caregiving experiences of mothers of children with T1D. Even though Canada has one of the higher rates of T1D (Patterson et al., 2014), studies with a Canadian context have not been conducted. Caregiving experiences may be different in Canada, where the health care system is publicly administered. In this study, we aimed to fill this knowledge gap by exploring the caregiving experiences of mothers of children with T1D in northern Alberta, Canada. Understanding the maternal caregiving experiences of mothers in Alberta will help to provide an understanding of the supports needed to alleviate the distress and increase the well-being of this population, as well as that of their children with T1D.

Methods

Study Design

We used a qualitative descriptive (QD) method to examine the caregiving experiences of mothers caring for children with T1D. A QD approach aims to describe participants' perceptions and experiences of the phenomenon by providing a rich description or focused summary of their experiences using their own words through a literal description of the data (Bradshaw et al., 2017; Neergaard et al., 2009; Sullivan-Bolyai et al., 2005). Using a QD approach to research involves staying closer to the data in the analysis and presentation process than in other qualitative approaches, where the aim of analysis may be a reflective interplay with existing theories; QD's interpretation beyond mere description (Neergaard et al., 2009) can lead to specific support-related suggestions drawn directly from the data. This study was approved by the University of Alberta Health Ethics Review Board (Pro00104580).

Participant Recruitment and Inclusion and Exclusion Criteria

We recruited mothers from northern Alberta who were caring for a child under the age of 18 with a T1D diagnosis for 12 months at minimum. The decision to include mothers with children under the age of 18, rather than focusing on a narrower age range, allowed for a broad understanding of experiences across child developmental stages and supported recruitment, given the limited number of children with T1D. Recruiting mothers of children diagnosed at least 12 months prior to the study start date ensured that participants had a common shared foundation of experience with their child's diabetes management.

All participants were required to understand English to participate in the study. Exclusion criteria included mothers of children with additional comorbidities, such as heart disease or cancer, or major cognitive or developmental conditions, such as Down syndrome or autism, because such conditions would have made it difficult to distinguish which findings pertained specifically to caring for a child with T1D versus the other conditions.

Participants were informed of the study through a recruitment post on Edmonton T1D Facebook pages and a poster advertisement at the Pediatric Diabetes Education Centre (PDEC) in Edmonton, Alberta. Serving approximately 1,050 children and their families from northern Alberta annually, the PDEC provides assessment, emergency telephone support, education, referrals to other health care providers, treatment, and ongoing follow-up for children ≤ 18 years old with diabetes (Alberta Health Services, n.d.). Interested mothers contacted the lead researcher (TA) by email. After screening for inclusion and exclusion criteria, TA connected with each potential participant via telephone or Zoom (https://zoom.us/) for a 20-minute follow-up conversation to discuss the study and voluntary participation, answer questions, confirm interest, and schedule the interviews. Written informed consent was obtained from all participants.

Caregiver Engagement

Patient engagement in research, also known as public and patient involvement, emphasizes collaboration with and participation of patients and or their informal caregivers in research (Hamilton et al., 2018). We established a Caregiver Advisory Committee of three mothers of children with T1D to collaboratively carry out this research study. The experience of collaborators in health research contributes to enriching the quality, significance, and relevance of that research. The PDEC staff helped identify potential volunteers. The lead researcher (TA) conversed with interested volunteers over a Zoom call, explained the study, outlined their roles and responsibilities, and obtained informed consent. Advisory members met the same inclusion and exclusion criteria as study participants. Meetings with advisory members were held on an as-needed basis over Zoom, for a total of 10 meetings, lasting 75–180 minutes. For each meeting, TA prepared an agenda that outlined topics of discussion, updates, and areas requiring input. Advisory members assisted with the development of our data collection tools and provided insight and feedback on the coding framework and the themes generated. They offered invaluable guidance, added a vital caregiver engagement component, and enhanced the credibility of this study.

Sampling Strategy

We used a convenience sampling strategy to recruit mothers of children diagnosed with T1D from the PDEC and from relevant diabetes Facebook groups. This approach is useful when the target population meets practical criteria such as geographical proximity-(Etikan et al., 2016), giving us convenient access to mothers of children with T1D in northern Alberta. The quality of data collected was continually assessed through the depth and detail of information gathered during participant interviews, and the principle of data saturation was used to determine when enough in-depth data illuminating the topic of study had been obtained so recruitment could be concluded (Morse, 2015).

Study Setting

Data were collected from mothers of children with T1D living in northern Alberta. The province of Alberta is situated in western Canada, and for the purposes of this study, northern Alberta consisted of all communities north of the city of Edmonton, as well as the city of Edmonton itself—a large urban centre with an estimated population of 1 million people (Statistics Canada, 2022). Northern Alberta is characterized by its vast, sparsely populated landscape and diverse populations and Indigenous communities such as the Cree, Dene, and Métis. Access to health care resources varies across the region. Families in remote and rural areas often face limited availability of specialized pediatric diabetes care, whereas residents in Edmonton have direct access to the Stollery Children's Hospital and the PDEC. For residents in rural areas, harsh winter conditions for 5–6 months of the year may complicate diabetes management by limiting travel and, therefore, access to the services of the PDEC.

Data Collection

After obtaining informed consent, we sent all participants a link to complete a demographic questionnaire online (see Appendix A) to understand the diversity of mothers participating in the study and to describe the population for transferability of findings. In collaboration with the Caregiver Advisory Committee, we developed a semistructured interview guide on caregiving experiences as a mother with a child with T1D (see Appendix B). Two pilot interviews were conducted to refine the interview guide. Data from these pilot interviews were not included or analyzed. Once the interview guide had been refined and retested, we conducted interviews with participants between November 2021 and April 2022. Given the impracticality of conducting in-person interviews during the COVID-19 pandemic, all interviews were conducted virtually through Zoom. Each participant was interviewed for approximately 75–90 minutes. Semistructured interviews allowed for an individualized and private space for mothers to share potentially difficult experiences. It also allowed more control over the pace and direction of sensitive conversations. Participants were asked probing questions to clarify their responses and obtain examples and further details or context. All interviews were digitally recorded, transcribed verbatim, and verified by TA for accuracy.

Rigour

Due to the focus of QD on rich data description rather than mere interpretation, the susceptibility of researchers imposing their subjective interpretations onto the findings is arguably less in a QD study. Yet, researcher subjectivity and transparency still need to be recognized (Bradshaw et al., 2017). The lead researcher (TA) engaged in reflexivity by considering her own assumptions, preconceived expectations, social position, and experiences by journalling throughout this research. Furthermore, to demonstrate data credibility, interviewees were given the opportunity to review their verbatim transcripts to verify accuracy, expand on their comments, and make any necessary revisions. Ten individuals took the opportunity to review their verbatim transcripts. Data credibility was also achieved by ensuring interviews were of sufficient length to generate detailed data. Dependability, or ensuring logical, traceable, and clearly documented research, was ensured by creating an audit trail documenting the procedures, decisions, and changes that were made throughout the study.

Data Analysis

NVivo 12 was used for data management, including documenting research decisions and modifications. Following Braun and Clarke’s (2006) steps for analyzing data thematically, TA coded and analyzed the data. This process involved TA immersing herself in the data by repeatedly listening to the audio recordings and rereading all the transcripts. After generating the initial codes, TA conducted an iterative process of refining and collapsing codes that overlapped and separating those that addressed distinct ideas. This process continued until codes were organized into clusters of similar ideas. The Caregiver Advisory Committee members were consulted throughout the data analysis process and provided feedback and insights on emerging themes. Ultimately, six themes summarize the key findings of the data collected.

Findings

Characteristics of the Participants

A total of 16 mothers whose average age was 37.1 ± 6.1 participated in the study (see Table 3.1): 14 participants self-identified as being White and Canadian-born, two individuals identified as Aboriginal or Indigenous, and English was the primary language for all participants. One mother identified as being engaged, 13 mothers identified as being married or in common law relationships, and two shared that they were separated but not divorced from their spouses. Women in this study had mothered one (n = 5; 31.3%), two (n = 8; 50.0%), or three (n = 3; 18.8%) children. Each participant had only one child diagnosed with T1D, for a total of 16 children whose average age was 7.8 ± 3.2 and whose average age of T1D diagnosis was 5.1 ± 3.1. Of those children, 11 were male (68.8%) and five were female (31.3%).

Table 3.1

Demographic Characteristics of Participants

Participant characteristics	Results	
	n	%
Age (years) [a]		
21–30	2	12.5%
31–40	7	43.8%
41–50	7	43.8%
Marital status		
Engaged	1	6.3%
Married/common law	13	81.3%
Separated but not divorced	2	12.5%
Divorced	0	0.0%
Widowed	0	0.0%
Number of children under 18		
One child	5	31.3%
Two children	8	50.0%
Three children	3	18.8%
Education		
Less than high school	0	0.0%
High school diploma or equivalent	1	6.3%
Registered trades or apprenticeship certificate/diploma	2	12.5%
College, cégep, or other nonuniversity diploma	8	50.0%
Undergraduate degree	3	18.8%
Advanced degree (e.g., MD, master’s, doctorate, professional degree)	2	12.5%
Employment status		

Participant characteristics	Results	
	n	%
Unemployed but seeking work	0	0.0%
Stay-at-home parent	2	12.5%
Self-employed (part-time)	1	6.3%
Self-employed (full-time)	2	12.5%
Part-time employee	3	18.8%
Full-time employee	8	50.0%
Racial, ethnic, and cultural background		
White	14	88.0%
Aboriginal or Indigenous (First Nations, Métis, or Inuit)	2	13.0%
Annual household income		
\$0–\$29,999	0	0.0%
\$30,000–\$59,999	1	6.3%
\$60,000 to \$89,999	0	0.0%
\$90,000 to \$119,999	4	25.0%
\$120,000 to \$149,999	6	37.5%
\$150,000 or more	5	31.3%
Area of residence		
Rural	8	50.0%
Urban	8	50.0%

Note. $N = 16$.

[a] *SD* = 37.12 ± 6.11.

Six themes emerged from the interviews with mothers in this study: (a) “I am the organ”: a sense of constant vigilance, (b) accepting a new normal, (c) grief underlying a rollercoaster of emotions, (d) caregiving as an isolating experience, (e) the continuous glucose monitor (CGM) is a champion, and (f) finding the positives.

We present each in turn with representative participant quotes, lightly edited for readability. To protect the participants' identities, we have used pseudonyms in place of their real names.

Theme 1: "I Am the Organ": A Sense of Constant Vigilance

The obligations involved in caring for a child with T1D require constant monitoring and proactive management. Mothers in this study described feeling an intense sense of relentless responsibility in their caretaking duties and a constant sense of vigilance for their child's well-being. Nearly all the mothers interviewed explained that a T1D diagnosis, unlike other chronic conditions in children, relied greatly on their presence and involvement for management and even survival. Although mothers acknowledged the involvement of care they shared with their partners, they described themselves as the primary caregivers for their children. One mother explained:

> As the caregiver, I make all the decisions in what he eats or what the carb count is or, you know, where he goes or what he does. No matter what's going on. Even if he says to his dad, "Can I do this?" [His dad will say,] "Well, let's go ask your mom. Check with mom. Can you eat that? Check with mom." You know, that is just my life. His care is my life. (Ellen)

Another mother of a 12-year-old boy explained her vital role in her child's T1D management:

> You know, 24/7, you're that organ. So, 24 hours a day, it's keeping things in mind. What he's eating, what I'm going to make for breakfast, what I'm going to make for supper, how it's going to affect him. It's my full-time job. (Liz)

A third mother echoed the importance of her role for her 3-year-old daughter's T1D management by also sharing sentiments of feeling like an organ for her child. She expressed: "But with this [disease], you're the organ. You are deciding, you're dosing. You're deciding he needs extra insulin, or less insulin, or whatever it is, and you have to be constantly available" (Nancy).

Whereas constant vigilance was described in daytime undertakings, such as engaging in continuous glucose readings, watching the child's physical activity levels, and monitoring dietary intake, participants highlighted the over-attentiveness they felt, especially during nighttime T1D monitoring. Many mothers feared hypoglycemic occurrences happening in their child's sleep and consequently found themselves repeatedly waking up to check their child's glucose levels. One mother of a 7-year-old boy recounted her experiences:

> I wake up several times in the night. I set alarms, and I look at my phone, and if I'm ever getting out of bed, I just go and look at him. I don't know. It's irrational, but I'm like, "Are you alive?" And I know he's alive because he wouldn't get a blood sugar reading if he wasn't. It's irrational. But you just worry, and I'm terrified of missing lows in his sleep. (Dianne)

Another mother shared:

> Yeah, the most stressful time is when he's sleeping. So, the time when you would expect to relax, knowing your kid is safe, is actually the opposite for us. Those are the times that you worry because they're not awake, you're not watching them constantly, and so you have to wake in the night periodically to check. (Janet)

As a result of constant nighttime checks, sleep deprivation and lack of quality sleep were common complaints among participating mothers. Alexa shared, "I'm exhausted 24/7. I'm mentally and physically and emotionally drained 24/7. I go to bed every night with anxiety, wondering if my phone is going to be screaming at me at three in the morning."

Another mother added:

> It's so hard because I hear that alarm in my sleep, and in my dreams, I hear that alarm. The low alarms, the high alarms. Like, I hear them even if I don't wake up right away. They literally will penetrate into my dreams. So yeah, usually I average one to two hours of deep sleep in the night. (Nancy).

Being vigilant as a caregiver also involved always being prepared to manage diabetes symptoms. Many participants attributed this requirement to the unpredictability of T1D. For example, one mother stated, “We have to plan before we do anything. Every time we leave the house, we take stuff. There’s so much . . . that I can’t even think of because they’re part of our routine and normal, you know?” (Amy). Another participant said,

> [Preparation] is just so ingrained into your life. Right? You know, you have sugar everywhere, . . . and then you have pokers [lancets] everywhere. Now I have a poker upstairs, downstairs, purse, car, you know, like everywhere. . . . It’s just the life of a diabetic. (Emily)

The age of the child played an important role in the intensity of responsibility and vigilance mothers felt. Mothers of infants and young children felt a greater sense of caregiver burden compared to mothers of preteens or teenagers. Part of this burden stems from younger children being unable to express their symptoms, making it harder to detect and treat potential glucose highs or lows and glycemic incidents without consistent monitoring. Younger children are also less capable of being involved in their diabetes care, placing T1D management primarily on their caregiver.

Mothers of younger children expressed their intense anxiety around caregiving and need for vigilance through sentiments such as the following:

> So, [my child] was diagnosed at 10 months. Having a baby with type one is extremely difficult, cuz he couldn’t talk. He didn’t even know how to walk just yet either. So, understanding if [he] was hungry, or if he was having a low or a high, and not fully understanding how he was feeling, was extremely difficult, just because he couldn’t express any of that to us. (Hailey)

At the same time, mothers of younger children shared feeling comforted by the idea that having a diagnosis at an earlier age had some advantages. They felt that it prevented their children from knowing a life before diabetes. Some participants shared that they were content with being the ones to bear the burden for their child’s care despite the hardship involved. One mother of a 9-year-old girl reflected:

> At least now, with diabetes having been a part of her [childhood], it’ll just grow with her. And I know there’ll be issues down the road, I anticipate them, but I don’t have to worry

> about introducing something new to her life at the same time that she's going through a huge upheaval like dealing with puberty or body image. (Ellen)

Another mother echoed similar sentiments:

> In a way, I'm kind of glad he was younger [when he was diagnosed] because he didn't establish routines of things that he likes to eat . . . and then at 7 years old have to drastically change the way he does things. Right? [My child] doesn't know any different. He doesn't remember not having diabetes. He'll never have that pain of knowing what life was like before diabetes. (Sharon)

Most mothers found it difficult to envision detaching from their role as a caregiver. Given their range of concerns, many hoped that they would be able to stay involved in their child's health care needs long term in some capacity, even when the child had become an adult. They felt that this would give them peace of mind.

Theme 2: Accepting a New Normal

Caring for their children with T1D involved making lifestyle changes and accepting a new sense of normalcy. Postdiagnosis, mothers were required to be adaptable, open to and welcoming of new routines, and ready to forgo some past lifestyle practices to accommodate the management required in T1D care. Several mothers described their experience of stress with their lifestyle adjustments, such as this comment from the mother of an 11-year-old girl:

> So, I guess from there we just . . . found our new normal. And I don't know, it's just a constant [struggle]. We're learning every day, and there's always something else, a curve ball that diabetes throws at you, that you weren't expecting. (Alexa)

Hailey described how many aspects of the family's lifestyle had changed, including food choices:

> The way we used to eat or look at food, exercise, health, how we talk about food—what else is there? There're so many things that we've changed. Before it was all about eating organic and nutritious, and not using sauces and stuff, and not having cereals or granola bars in our house. Well, [now] we kind of have to have those things in here. Right?

Sharon, who had a 7-year-old boy, stated,

> We don’t leave the house the same way. We don’t eat the same way. We don’t travel the same way. I feel like everything is different. Yeah. Huge changes; just enormous. I mean, my life has been, I think it’s been ruled by diabetes now. It’s like, I [say] . . . that we live our life based on diabetes.

Another part of a new reality that mothers described involved being unable to spend alone time with their significant others or to spontaneously attend social outings, as they had prior to the diagnosis.

> [The T1D diagnosis] has affected my social life [and] my mental and emotional factors in my life. And even, you know, my personal life with my husband. . . . There’s been times that we’re alone, and all of a sudden alarms start going off, and then it’s like, “Oh, well, we need to deal with that.” So sorry, off we go. (Chloe)

Many mothers also described their inability to travel or generally spend time away from their children without overly planning their child’s care needs first. When they did, they needed to monitor their child’s CGM readings and still be available to answer questions via phone calls. Nadia, a mother of a 6-year-old, explained: “My personal freedom, I guess, is changed until she gets older. No matter what I’m doing, I need to be available. So, it limits what I can do or where I can go.”

Even during the workday, mothers watched CGM readings. This vigilance required them to stay in jobs that allowed this flexibility, limiting their career choices and advancement opportunities. This limitation was felt even more by mothers who were separated from their spouses. They felt that their single incomes prevented them from taking career-related chances. They feared financial losses, losing schedules that allowed them to care for their children, or losing their positions altogether while juggling caregiving duties. A mother of a 9-year-old explained:

> I think the biggest thing that it [T1D] took over was my job. I love my job and I used to work 200 plus hours a month. But once he was diagnosed, it was like, “What’s the bare minimum that I can do to still get the experience and fulfil that part of my life, but still be there and be the primary caregiver for him?” (Emily)

Many mothers attributed these lifestyle changes to the unpredictability of T1D and a lack of knowledgeable and available respite care. Two mothers, for example, expressed similar responses. Hailey noted: “I can’t even imagine, I don’t even know, what it’s like to just pick up and go somewhere. There’s so much planning for everything”. Similarly, Mandy described,

> We haven’t been on holidays, my husband and I, since he’s [our child] been diagnosed. But as far as, I guess, going out for the night, we just started taking the kids everywhere we went. I can’t even really go away for a day without him [my child with T1D], not with the . . . childcare we have in our family.

Other mothers anticipated their lifestyles to continue to evolve with their child’s care needs and developmental age, which would require them to remain flexible and amenable to change. For instance, a mother of a 3-year-old with T1D explained:

> Every couple of years, you have to adapt and change because kids grow. You know, my 10-month-old is definitely not the same kid as my 3-and-a-half-year-old. She’s a very different child. [When she was younger], . . . I could just deal with it [diabetes management] and do it. Now, she’s a lot stronger. She’s a lot more capable. She’s a lot more understanding. She says, “No, Mommy, I don’t want any more insulin. No, Mommy, I don’t want my pod changed.” Whereas before it was just—she didn’t know any better. So, it definitely changes in layers, kind of, as the child ages. (Nancy)

Theme 3: Grief Underlying a Rollercoaster of Emotions

All mothers interviewed described the various emotions they felt throughout their journey as caregivers. They also discussed the trajectory of their emotions and how they shifted and developed into other emotions with the passing of time. Early shock and denial led to day-to-day anxieties, and then to long-term anxieties, with grief as the underlying and lingering experience. During the diagnosis process, mothers commonly experienced a wide mix of feelings, including anger, guilt, confusion, denial, grief, panic, and shock. A mother of a 7-year-old boy, for instance, reminisced about her experience and shared:

> The best way I describe it is I felt like I was hit by a train, when he [the doctor] came in and told me it was type one diabetes. I just—it was the end of the world. Everything would be different. I was sure that life, as we knew it, was over. And you know, I cried and cried and cried, and this was the worst thing that could happen. And why me and

> why him? Like, why him? He's just an innocent little boy who didn't do anything. It was really hard for me to come to terms with it. (Brooke)

Whilst working through the shock of their child's diagnosis, anxiety, and uncertainty about being able to manage T1D were prominent emotions consuming the minds of the mothers. Taking their children home from the hospital and being responsible for their care was terrifying for them. Mothers worried that they would make deadly mistakes, and the burden of responsibility felt overwhelming. For example, the mother of a 5-year-old boy explained:

> My worries were very, I think, practical in the beginning. You know, can I give him needles? Will I test his blood sugar right? Will I make the right decisions about what to feed him? Will he be okay? . . . Am I going to be able to manage this? Like, am I able to keep him safe? Is he going to be healthy? Is he going to go low overnight, and I'll sleep through it and not know, and he'll have seizures and whatever? (Mandy)

Anxiety and doubt experienced during the early postdiagnosis period were influenced by the quality of care and training mothers perceived that they received from health care staff and their support networks. The mothers who felt they had received sufficient information about managing T1D, had ongoing emotional support, and had knowledgeable and responsive health care providers for their children felt more reassured in their ability to manage.

Whereas, over time, mothers began to feel more confident in their ability to care for their children's condition, easing some of their initial day-to-day anxieties, they also became more apprehensive about the future. Mothers worried about how T1D would affect their child's quality of health and how well their children would be able to manage their diabetes. For example, the mother of a 5-year-old boy shared this concern:

> You know, I've thought about him living on his own and having a low and not [being] able to get himself to the fridge to get juice. And I've thought about the life expectancy, that it can be lower for diabetics. And like, what if he's too high for too long? And he loses his vision. What if he—you know, I've thought about all of it, and it's so stressful because I can't control it. I can't predict it. I don't know what's going [to happen]. I can control today, but I can't control 10 years from now, but yet I can't not think about 10 years from now. (Hailey)

Another participant expressed a similar sentiment:

> My biggest fear for him is moving out of our house. I think about it all the time, and he's only seven. . . . [I also worry] that we're not going to be able to teach him enough, or I don't know, his experience with life is going to be so different than any other person, and that sucks for him. You know, he has such a wild heart. Like, all he wants to do is travel the world. And all I can think in my head is, "Oh my God, how are you going to travel the world with type 1?" (Sharon)

A final example of future apprehension comes from the mother of a 9-year-old girl:

> A big one right now for me is eating disorders. We have to look at food. We have to look at what we eat. We have to look at macros and carbs and protein and fat, how that'll react in her body. So, making sure we do that in a way that isn't going to cause issues down the road, like an eating disorder where she starts counting the wrong things or carbs are bad or sees messaging out there that's not healthy around diet culture and how that reacts to her. (Chloe)

Other mothers were concerned about the financial strains T1D would impose on their children as adults. A mother of a 12-year-old boy shared:

> I worry about [my child] getting a good job to be able to pay for his own medical supplies. I sadly have already taught him from now to get a good job. I say, "You need to be able to afford this. And this [T1D] costs a lot of money." I have to make sure that [my child] has a great education. (Liz)

Participants likewise worried whether their child with T1D would be viewed negatively or ridiculed by others. Ellen, for instance, explained: "I wonder if she will be able to find a romantic partner okay. What if her diabetes stands in the way of being truly accepted?" Tracey shared,

> For me, I worry about when his care is out of my hands when he goes to school. . . . I worry about what other kids are going to say. You know, if he's going to get bullied because of this [his T1D] or treated differently.

While reflecting on the course of their emotions, many participants shared that underlying the shock, fear, anxiety, and future stressors that they felt, grief was a central and an unceasing feeling, one that they anticipated always having to bear. Two mothers described the relentless and lingering feelings of grief they felt. The first one shared:

> I call it the fog. I literally, like you just ask yourself, "When am I going to stop crying about this?" Every time you think about it, you cry. Every time you realize this your life for now, forever, you cry. Every time you think about, oh, your kid can never just go and do this or that. And I don't know, actually, if I've ever really been done grieving. It's been 8 years, and I'm still this emotional talking about it. [Cries.] (Leslie)

The second mother said,

> There's this primitive part in the back of my brain that hasn't stopped screaming at me. Like, your child is in danger, your child is sick, and it will never, ever get better. So, I live my life in this weird nether zone between "everything's fine and we're doing well and he's thriving" and "oh my God, he could die at any second." It crushes me with sadness. It's a very bizarre way to live your life. (Dianne)

In addition to the grief participants felt for the health of their children and for the life their children have been robbed of, mothers also grieved for the loss of their own lives, the simplicity of life prior to the T1D diagnosis and for having to accept a new normal. The chronicity of T1D and it being an incurable condition further exacerbated this feeling. As one mother explained:

> I can remember a life where I wasn't checking a reading. I can remember that life, and I miss it a lot. I remember we could go out for dinner, and I didn't have to look at her food and . . . make calculations in my head or on my phone or write things down. So, I do miss it. I miss it a lot. (Nadia)

According to one mother, she explained the grief of losing her prediabetes lifestyle:

> One of my biggest challenges in all this has been keeping my identity, like not just being [my child]'s caregiver [crying], being myself too. When you're a caregiver, your entire life is revolved around that child. Everything, like literally everything. Like even trying to go have that bath or a shower, or just [have] time to myself. It's non-existent when you're a caregiver. (Ellen)

Theme 4: Caregiving as an Isolating Experience

Mothers shared that they have faced various stigmas and misconceptions about T1D that have led to feelings of isolation for them as caregivers, also making it hard for them to discuss their child's T1D with others. A common complaint was that the public lacks awareness of the difference between type 1 and type 2 diabetes (T2D).

One mother expressed her frustrations:

> My biggest struggle is with the ignorance or the comparing to type 2. Let's just be honest, that's what people think of, right? I wish they had a different name for Type 1, to be honest. . . . Generally, with type 2, you have a warning, you can make changes, and you won't end up with it. People just don't understand T1D. It's not the same challenge. It's not the same experience. (Janet)

Other mothers shared that people's misconception that T1D can stem from unhealthy lifestyle choices, like T2D does, instead of from genetic and environmental causes, made them feel misunderstood and indirectly blamed for not being able to manage their child's T1D with lifestyle modifications. Participants expressed that such assumptions downplayed the complexity of their child's condition and their challenges as caregivers. One mother explained:

> I mean the number of comments we've had from people, like "she can grow out of it right?" Or to have to explain, "No, she can't diet her way out of this. A low carb diet isn't going to fix it." Like, it's a problem with her organ. It's exhausting. And it makes me scream when people say stupid things like "maybe she won't need insulin if you just put her on a ketogenic diet." (Ellen)

Another mother said, in a disheartened tone, "The world just doesn't understand the scope of it, I don't think" (Nancy).

Mothers maintained that those who do not have knowledge of T1D or do not have a chronically ill child cannot fathom the complexity of a T1D diagnosis, its associated challenges, and the constant management involved. This observation left them feeling alone in their experiences. In fact, many participants said that their participation in the study interview was one of the few times, if not the only time, that they had shared their experiences as a caregiver. The mother of an 11-year-old girl said,

> This is like the most in-depth conversation I've had about how I'm doing with all of it or how I feel or how I'm grieving. I've never had anyone really say, like, "How are you?" Or like, "Have you guys [her and her partner] got a date night lately?" (Alexa)

Although some participants explained that their extended family members and friends tried to be supportive, many also found that others pulled away from them and their children. They attributed this behaviour to apprehension and a lack of knowledge about T1D:

> So, my family was very, very close. And then as soon as [our child] got diagnosed, they all pushed us away. It was like we had the plague. Like literally, they were absolutely terrified of [our child]. I'm like, "He's not going to combust on you guys. [Laughs.] It's okay; . . . it's not contagious. You don't need to be afraid." (Hailey, mother of a 5-year-old)

To combat the isolation, mothers expressed turning towards and finding comfort and understanding from other parents of children with T1D through online platforms such as Facebook and programs run by the Stollery PDEC in Edmonton. Unfortunately, COVID-19 safety measures disrupted the programing of in-person events, leading to an increased experience of isolation for mothers and their children during the pandemic.

Theme 5: The CGM Is a Champion

Amidst the T1D care management challenges described, all mothers also expressed an immense appreciation for the factors that made their caregiving experience more bearable. In particular, access to a CGM, such as the Dexcom (https://www.dexcom.com/) or Freestyle Libre 2 (https://www.freestyle.abbott/ca-en/freestyle-libre-2.html), was highlighted as life changing. For instance, Amy shared: "But the Dexcom, I would say, would be the number one thing that has helped us through his diabetes. I don't know how people survive without it."

Another mother agreed that this technology made a pivotal difference:

> If I had to say one thing that could be life changing for all diabetics, it would be a CGM—access to a CGM that's covered. Cause it just gives you so much peace of mind. I can't imagine having to get up in the middle of the night, every single night, to know what her blood sugar is like. We did that for a month, and I said, "Nope, I can't do that anymore." So, yeah, that's a big, big, big, big, big one, tech wise, for sure. (Chloe)

Emily, mother of a 9-year-old boy, similarly described having a CGM as life changing:

> A big thing was when we got his blood sugar monitor, his Dexcom. It was a really big—I call it a life-changing—thing for me because it was peace of mind for me that I could know how he was doing at that time, and I didn't have to know exactly where he was, what he was doing.

Some mothers also shared that the CGM reduced their anxiety while their children participated in normative childhood activities. The mother of a 7-year-old boy explained:

> And the Dexcom is so huge in the way that I'm able to monitor his numbers all the time. And that's why I'm comfortable sending him to school. That's why I'm comfortable with him taking the bus. That's why I'm comfortable with him out riding his dirt bike, cuz he wears a fanny pack with his phone in his pocket. You know, without it, don't know how I would be. (Brooke)

Other mothers highlighted the way the CGM improved the quality of sleep for their children, their partners, and themselves: "Yeah, sleep is better because of course we have Dexcom. We don't have to physically get out of bed and do a finger check a couple of times a night, we don't have to do that" (Leslie). Similarly, Nadia, said:

> I can't imagine life without it. It makes things so easier to see trends, not just what she's at, but to see [what the] trends are. [And] we don't have to wake her up in the middle of the night to check her blood glucose.

Despite the many benefits of a CGM and the huge step forward in care has enabled, it is not a permanent solution. As such, it has also introduced some challenges. As the mother of a 2-year-old boy shared,

> His Dexcom is the best thing ever, but . . . it can almost be too much because every five minutes you get a new blood sugar reading. I could just stare at my phone all day and just watch it [the readings]. So that's a bit tough as well, and tough to be present, you know, when you're hanging out with friends or trying to take some time for yourself. It's difficult to shut that part of your brain off—which I don't know that I can, to be honest. (Tracey)

The mother of a 7-year-old boy shared her challenges with a CGM as follows:

> And interestingly, getting the Dexcom introduced this whole new element of terror where I would see him drop low at school, and there was nothing I could do about it. In some ways it made things a lot better and in other ways, it made things harder: just a new piece of technology to think about, to worry about, to make sure that our orders came in on time. We were going through more insulin, [and we started to need to be] getting to the

> pharmacy more often . . . and learning new skills. Right? We had a couple of pod failures, and he started to collect ketones and skyrocket up in his blood sugar. And so again, it became a new set of signs to become aware of. (Dianne)

All mothers, however, emphasized that any disadvantages of the CGM were far outweighed by the positive ways in which it had impacted their lives. Each of them expressed that they would never give it up. One mother stated,

> The only downside to it is how expensive it is—incredibly expensive. And luckily for us, we have insurance coverage through my husband's benefits. But even if we didn't have insurance, I would move [laugh] heaven and earth to get that because it's just the amount of pressure it takes off and relief it gives. (Brooke)

Ellen, the mother of a 9-year-old-girl, echoed that sentiment:

> I know, in my heart, that that CGM has saved her life over and over and over again. And I would pay out of pocket for that. I would go without a lot of other stuff before I would give that up.

Theme 6: Finding the Positives

Although the participating mothers expressed that it was difficult to find positives in their child's T1D diagnosis given the complexities it added to their lives, they explained that identifying positives helped them to maintain a healthy mindset and gave them the strength to continue to manage such a difficult diagnosis. One positive was gaining confidence in their ability to care give over time through learning and experience. All mothers in this study highlighted their challenges with managing their child's diabetes and the intense emotions of grief, stress, and anxiety they have experienced with the diagnosis. Commonly, however, mothers also described that although many of these emotions still lingered, over time they have felt less overwhelmed and more capable to manage their child's T1D. For instance, a mother of a 6-year-old boy shared this shift by stating:

> In the beginning you're in survival mode, 100%, for a long time. I feel like survival mode is where you are. You take one minute at a time—not even day by day, it's literally minute by minute in the diabetes world. But over time you learn how to manage the highs and lows. (Amy)

Other mothers explained how, over time, they became more comfortable with their caregiving duties: “Well, certainly you get more comfortable with it, you know? There isn’t the same sense of worry. It’s not utter panic when you see the CGM is plummeting. It’s like, ‘Okay, let’s test and let’s treat and let’s monitor’” (Liz). Another mother attributed her less intense feelings of worry to having gained experience over time:

> It’s certainly less stressful, and I think that’s connected to having learned more and getting more familiar with what to do and having just some experience under my belt, so that I don’t panic anymore when he goes low or he goes high or alarms start going. And that’s just come with time, right? I am much more confident now in responding, implementing his safety plan, but also changing it on the fly when I need to—if we’re out or if something different happens, if he gets sick, if he’s busy, whatever. I feel much more like I have a handle on it. So yes, experience, practice, confidence. (Mandy)

A mother of a 2-year-old boy, echoed this idea and attributed her less-intense feelings of worry to having gained experience over time:

> The more that we know and the more that we educate ourselves and hear other people’s stories, the braver we become in managing his disease. . . . We’re just more confident in our decision-making. We know more so what to expect. It’s still stressful, but it’s less stressful. Like I said, it’s become just our norm. (Tracey)

With the passing of time making the routines and management of T1D more familiar, a few mothers also shared some silver linings. A mother of a 6-year-old girl, for instance, explained how her family’s perspective changed after the T1D diagnosis: “And none of that other stuff mattered anymore. Like the stupid stuff that we thought was the end of the world. So yeah, it brought us close together as a family and made us realize what is important” (Nadia). Another mother similarly shared:

> I think I don’t stress about the small things in life anymore at all. [Laughs.] When I returned to work, it was like a night and day situation. I think I see a bigger picture now. And it’s kind of freeing in that sense where you don’t sweat the small stuff anymore because you have something really big to sweat about. Yeah. Cause everything just seems so minute, and it doesn’t faze me anymore. . . . That’s my silver lining. (Alexa)

Other participants explained that their child's diagnosis allowed them to be more understanding of others and more patient overall. For example, one mother stated, "I'd like to say it teaches me more patience. It teaches me . . . about my child's resilience. It teaches me that my child has the ability. It reminds me not to micromanage" (Liz). In addition, a mother shared:

> And I think also more compassion for those dealing with these types of stresses in life as well. Yeah. Not that we didn't have compassion, you know, . . . [but we are now more] understanding of what it's like for those for parents, especially who have children with either a disability or a disease of some sort. You just want to do everything you can to help. (Tracey)

Another mother shared that her silver lining was that T1D brought her and her son closer together:

> So, we did get to spend a lot more time together, which never would've happened if he didn't have it. Right? He would've just gone to school, did his thing. I wouldn't have seen him all day, and I would've been at work. So, in a way I think that was kind of nice. And then all of our trips to Edmonton have been fun, you know, like our little getaways, just the two of us. So, yeah, I would say that was kind of a silver lining. (Leslie)

Discussion

This study highlights the maternal experiences of caregiving for children with T1D in northern Alberta, identifying six main themes. Mothers in this study described constant vigilance and anxiety while caring for their children with T1D, with some even identifying as their child's "organ." They also described frustration with assumptions and judgement from family members and those without children with T1D. These experiences led to a sense of isolation and feeling that their challenging role as caregivers was unrecognized. In addition to these feelings, participants described an overall underlying grief that remained persistent. Worrying about their children's future living with and having to manage T1D exacerbated this. Mothers faced accepting a new sense of normal, way of living and identity in order to accommodate their child's needs. Technology like the CGMs helped relieve some anxiety allowing mothers some freedom from constant monitoring and even improved the quality and quantity of sleep for the entire family. Over time an increased sense of self-confidence with managing the child's T1D diagnosis was experienced by the majority of participants interviewed. Emotional challenges, such as grief and anxiety, however, remained a part of the caregiving experience.

Caring for a child with T1D is life-altering for mothers, as they must adjust their routines and lifestyles to accommodate the demands of care management needs. The unpredictability of blood sugar highs and lows requires mothers to always be prepared, flexible, and willing to prioritize their child's needs. As a result, mothers feel a constant, all-encompassing sense of vigilance and responsibility for their children's well-being and health outcomes.

We found that nighttime routines present heightened responsibility of care and vigilance for hypoglycemic events, which can result in sleep deprivation and physical exhaustion for mothers. In addition to physical strains, mothers also experience social consequences, such as travelling less, giving up socializing with friends, and not having date nights with their spouse, as well as financial consequences, such as forgoing potential career advancement opportunities. Mothers who were separated from their spouses, especially, felt it was difficult to focus on career advancements. These findings are in line with previous research on how caregiving experiences adversely impact the social, financial, and physical well-being of mothers (Feeley et al., 2019; Khandan et al., 2018; Tong et al., 2022).

Our findings also corroborate other studies that have found that caregiving for T1D creates a significant psychological and emotional burden on mothers. Commissariat et al. (2020) reported that parents' worries about their child's future and possible long-term health complications contributed to their emotional burden. Similarly, participants in our study communicated profound ongoing concern about their child's future and the potential long-term health complications of T1D. Mothers in our study additionally expressed anxiety over long-term worries such as the financial consequences their children would face due to the cost of diabetes care, distress over their child's ability to manage their diabetes on their own, and the impact T1D would have on their children's future romantic partnerships, abilities to travel, lifestyle, and career choices. They felt that their children would have to continuously adjust their lives to accommodate for having T1D.

Further examining the emotional consequence of T1D on maternal caregivers, we found that grief is a consistent and lingering experience. These findings are aligned with an earlier study, which found that even after 7 to 10 years postdiagnosis, mothers feel grief, which the researchers called chronic sorrow (Bowes et al., 2009). In our study, mothers specifically mentioned grieving for the loss of normative life experiences and for the challenges their children would have as a result of living with T1D. Notably, mothers with children diagnosed at a younger age felt comforted by the thought that their children would at least never remember a life prior to the diagnosis to grieve for. Adding to the existing literature on grief and sorrow, we found that mothers also grieved for the comparatively carefree lifestyles and identities they had prior to their child's T1D diagnosis.

For some participants, the constant vigilance required to manage their child's T1D diagnosis impacted their sense of identity. They felt that so much of their lives was dictated by caretaking needs that their personal identities and needs were lost to their role as a caregiver. This perception was exacerbated by having to face various stigmas and misconceptions about T1D that isolated them. They could not share their experiences with their friends or other parents who had no exposure to caring for a child with T1D. In fact, for many mothers, this study was the first time they had participated in an in-depth conversation about their experiences as caregivers. Nearly all mothers stated that their participation in this study allowed them to feel heard, highlighting the importance and need for creating opportunities for mothers to share and connect with empathetic others about their child's T1D.

Alongside the challenges of caregiving, mothers mentioned some notable factors that have supported them in their journeys as caregivers. One such aspect has been gaining confidence over time through experience. With the passing of time, participants have gained confidence in their skills and become more knowledgeable about how to manage T1D. This competence has helped to reduce some of their anxieties around their daily caregiving duties. Although no data pertain specifically to caregivers of chronically ill children with T1D, some limited studies have mentioned the rewards of the caregiver role more generally. Positive feelings toward caregiving have been associated with lower levels of depression and perceived caregiver burden (Cohen et al., 2002). Studies have also shown that caregivers who report higher levels of positive aspects of caregiving report greater health and well-being, lower levels of identity loss, and better overall coping ability (Cohen et al., 2002; Walker et al., 2016).

Another helpful factor for mothers has been access to a CGM. Recent studies have associated the use of technologies such as pump therapy and a CGM system with lower caregiver burdens (Luo et al., 2022). Participants in this study, like other studies (Luo et al., 2022), associated access to the CGM with improved nocturnal glucose control, reduced hypoglycemia, better sleep, and a reduction in anxiety. They believed that the CGM was a necessity, one that all caregivers should have access to. Although mothers stressed that its benefits greatly outweighed its disadvantages, challenges with the use of the CGM were also mentioned, such as its constant output of data causing anxiety. Recognizing that the CGM can raise some anxieties, this finding suggests that when introducing CGMs to mothers, health care personnel should counsel them on how to cope with the real-time data at their fingertips.

These findings, together with previous research, add to the larger discussion on the importance of access to technology and psychological services for mothers of children with T1D. Specifically, mothers should have access to affordable and subsidized technologies, given the important role they play in reducing caregiver burden. Furthermore, ongoing and affordable counselling services should be made available to mothers, and family practitioners should recognize when to suggest mothers seek therapy. Counselling provided to family caregivers has been shown to improve coping skills, self-care practices, and low mood (Cuijpers et al., 2015). Based on our findings, mental health professionals could support mothers postdiagnosis with managing the stress and anxieties of caretaking duties, identifying and coping with grief, developing or regaining a sense of identity, building self-confidence as a caregiver, shifting their perspective to one of regaining hope, and recognizing “silver linings” or victories. Therapy could offer a space for mothers to feel validated, be assessed for emotional distress and burnout, and be given appropriate support and strategies to cope with their child’s T1D. Services should be delivered by trained professionals who not only understand the sequala of a T1D diagnosis, but also age at diagnosis and childhood development may uniquely impact a mother’s experience of caregiving. Given the lack of respite care mothers have access to, virtual counselling services should also be provided to remediate the possible challenges of in-person attendance. Beyond counselling, the development of groups dedicated to connecting mothers of children with T1D within communities may also serve as another form of therapeutic relief. Such groups can offer another way for mothers to feel connected, heard, and supported by other mothers who share similar struggles.

Even further, improving access to respite care for mothers is an important subject to consider. Many experiences mothers spoke of, such as the loss of time for themselves, the lack of date nights with their partners, and the weight of constant vigilance could be improved with access to trained respite care. For instance, T1D-specific training could be regularly organized and offered by the PDEC or community organizations to paid caregivers and family members, increasing the number of individuals who could serve as respite caregivers. Access to adequate respite care would potentially allow mothers to engage in activities they enjoyed prior to the T1D diagnosis, ameliorate their experiences of isolation, and reduce their caregiver burden, thereby increasing their sense of freedom. These findings and research implications could be transferable to similar populations and settings within Canada and possibly other high-income countries with a publicly funded health care system.

Other research indicates that parental psychological adjustments affect how well chronically ill children adjust to their diagnosis (Anderson & White, 2018; Pierce et al., 2017). Increased distress among mothers of children with T1D, for instance, has been found to predict simultaneous child psychological distress (Karlsson et al., 2008; Rechenberg et al., 2017). Studies have associated greater parenting stress and anxiety with deteriorating glycemic control management, which raises the risk for short- and long-term disease-related complications (Cousino & Hazen, 2013; Rechenberg et al., 2017). Improved mental well-being of mothers through increased access to appropriate services and supports therefore also serves to improve the well-being of their children with T1D, which would ultimately further reduce concern among mothers.

Limitations and Strengths

This study is the first to explore the experiences of mothers of children with T1D in Canada. It is also novel in that it was developed in collaboration with three caregiver advisors who are mothers of children with T1D. A caregiver engagement approach allowed us to draw on the invaluable and first-hand experience of mothers of children with T1D to develop meaningful and essential interview questions, resulting in the generation of rich data. Additionally, although this study was limited to participants who predominantly identified as White, English-speaking, and with access to health insurance benefits, there was some diversity of study participants, with differing marital status, variation in the age of the participants and their children, and two individuals who identified as Indigenous or Aboriginal. Further research is required to better understand the experiences of single mothers, mothers from more diverse ethnic backgrounds, those from lower income brackets, and those with English language barriers, as these factors may influence the experience of care, access to support, the financial implications, and overall caregiver burden. Finally, although our inclusion criterion for age was broad and allowed us to capture the experiences of mothers with children under 18 years of age, no mothers with children over the age of 14 volunteered to participate. This limitation instigates the need for future studies aimed at understanding the experiences of mothers of older children or teenagers with T1D. Developmental factors such as puberty and shifts in responsibility of care from mother to child during the teenage years may influence the overall caregiver experience and would be valuable to explore.

Conclusion

This study adds to the literature by sharing experiences of mothers of children with T1D from a Canadian context. Like other studies, we found that mothers in northern Alberta experience considerable anxiety and demands from treatment management that are life altering. Although mothers try to effectively step into their caregiver role by adopting new lifestyle modifications and routines, relying on technology, and finding comfort in support networks, mothers still bear a significant amount of responsibility and stress, which may lead to an experience of lingering grief. Novel in our study was that, despite differences in participant demographics such as age, age of their child with T1D, marital status mothers shared similar anxieties, a sense of constant vigilance, and lingering grief. Mothers also consistently associated improved quality of life and sleep with access to a CGM and associated lifestyle changes with a lack of access to respite care. Despite Canada's health care system being publicly funded, many of the challenges and experiences highlighted by participants in this study are similar to discussions in previous studies. Findings from this study further underline the importance of ensuring that mothers have access to mental health services, continued and consistent support from health care providers, respite care options, and access to affordable technology such as CGMs.

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Appendix 3A: Online Demographic Questionnaire

1. **How old are you?** ______ (Enter value)
2. **What is your current marital status?**
    - ○ Single
    - ○ In a relationship but not cohabitating
    - ○ Engaged
    - ○ Married/common law
    - ○ Separated/ but not divorced
    - ○ Divorced
    - ○ Widowed
3. **How many children do you have under 18?** _______ (Enter value)
4. **How many children do you have with T1D under 18?** ________ (Enter value)
5. **How old is your child with T1D? (If you have more than one child with T1D please list the age for each child).**

    Child 1: ________ years and ________ months (Enter values)

    Child 2: ________ years and ________ months (Enter values)

    Child 3: ________ years and ________ months (Enter values)
6. **What is the sex of your child with T1D? (If you have more than one child with T1D please list the sex for each child).**
7. **At what age was your child diagnosed with T1D? (If you have more than one child with T1D please list the exact age of diagnosis for each child in years and months e.g., 4 years and 2 months.**

    Child 1: ________ years and ________ months (Enter values)

Child 2: ________ years and ________ months (Enter values)

Child 3: ________ years and ________ months (Enter values)

8. **a. How many people live in your household (including yourself)?** ________ (Enter value)

   b. How many of these individuals are under 18 years of age? _____ (Enter value)

9. **What is the highest level of education that you have completed?**
   - ○ Less than high school
   - ○ High school diploma or equivalent
   - ○ Registered trades or apprenticeship certificate/diploma
   - ○ College, cégep, or non-university diploma
   - ○ Undergraduate degree
   - ○ Advanced degree (MD, master's, doctorate, professional degree, etc.)

10. **What is your current employment status?**
    - ○ Unemployed but seeking work
    - ○ Stay at home parent
    - ○ Self-employed
      - ○ Part-time
      - ○ Full-time
    - ○ Part-time employee
    - ○ Full-time employee

11. What is your total annual household income?

An approximation of your total annual household income before taxes, from all sources, including wages, rent from properties, social security, disability benefits, help from relatives and so on.

○ $0 to $29,999

○ $30,000 to $59,999

○ $60,000 to $89,999

○ $90,000 to $119,999

○ $120,000 to $149,999

○ $150,000 or more

12. Were you born in Canada?

○ Yes

○ No

13. If you answered no to the previous question, in what year did you immigrate to Canada? _______ (Enter value)

b. What country did you immigrate from? ___________

14. Is English the primary language spoken in your home?

○ Yes

○ No

15. If you answered no to the previous question, what is your primary language? ________

16. How would you describe your racial, ethnic, and cultural background?

Please feel free to provide more than one answer if you have several backgrounds.

○ White

- ○ Aboriginal or Indigenous (First Nations, Métis, or Inuit)
- ○ East Asian (Chinese, Japanese, Korean)
- ○ South Asian (e.g., East Indian, Pakistani, Sri Lankan)
- ○ Southeast Asian (e.g., Filipino, Thai, Indonesian, Vietnamese)
- ○ Black or African Canadian
- ○ Latin American
- ○ Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
- ○ Do not know

17. What town/city do you reside in (e.g., Edmonton, Grande Prairie, Leduc)? ________

Appendix 3B: Semistructured Interview Guide

What are the experiences of mothers in northern Alberta caregiving for type 1 diabetic (T1D) children under the age of 18?

1. Tell me about your experience caring for your child who has T1D. *If you want, you can start from the beginning, like when you found out your child had T1D, and work your way up to today. I want to hear your story about caring for your child in as much detail as you're comfortable sharing.*
2. How has caring for your child who has T1D affected your life?
3. How has your experience of caring for your child with T1D changed over time, if at all?
4. Describe for me your typical weekday caring for your child, starting from when you wake up until you go to bed. *If you want, you could think about yesterday (or Monday, etc.) and describe it.*
5. Describe for me your typical weekend caring for your child. *If you want, you could think about this past weekend and describe it.*
6. What are the biggest challenges you've faced/experienced when caring for your child with T1D, if any?
7. What are the things that have helped you in caring for your child with T1D, if any?
8. What, if anything, has been positive in your experience or an unforeseen silver lining in caring for a child with T1D?
9. Is there anything else you'd like to share with me about your experience caring for a child with T1D?

Examples of Probes

- What do you mean when you say, "[Statement in question]"?
- How come/so?

- Can you tell me more?
- What does that look like in everyday life?
- What else? Can you give me an example?
- Is there anything else you can think of?
- Can you tell me what that's like for you?

Probes to Redirect Participants Back to Their Experience (of That Experience)

- What's that like for you?
- And how did you feel about this/that?
- How do/did you deal with that?
- What helped you/would have helped you (with that/ in that situation)?

Directive Subquestions If Participants Are Feeling "Stuck" With the Main Interview Questions

- Tell me about your experiences around childcare.
- Tell me about your experiences of your child going to school.
- How has caring for your child influenced you emotionally, mentally, spiritually, socially, and financially (if at all)?
- How has caring for your child influenced your career (if at all)?
- How has caring for your child influenced your relationships (if at all)?

Chapter 4: Exploring the Support Needs of Mothers of Children With Type 1 Diabetes in Northern Alberta: A Qualitative Descriptive Analysis

The objectives of this third and final study were to understand the support needs of mothers in rural and urban northern Alberta living with children with T1D under the age of 18. My coauthors were Lisa Wozniak, Richard Oster, Jeffery Johnson, and Stephanie Montesanti. The manuscript was submitted for publication in August 2024 to *BMC Women's Health*. To fit this dissertation, I have reduced major headings by one level, and I have included the chapter number in the table numbers. No other changes have been made to the original submission.

Chapter 4 Abstract

Objectives: Typically diagnosed during childhood, type 1 diabetes (T1D) profoundly impacts the lives of those diagnosed and their primary caregivers, who are usually their mothers. Management of T1D involves constant blood glucose monitoring, insulin administration, and dietary adjustments, which have psychological, physical, social, and financial consequences on mothers as caregivers. Despite the critical role mothers play in managing their child's condition, understanding of their specific support needs is limited, especially within the Canadian context, where the prevalence of T1D among children has been rising. This study explored the support needs of mothers caring for children with T1D in northern Alberta. **Methods:** A qualitative descriptive methodology with thematic analysis was used to gather data from diverse perspectives. Twelve participants, all mothers of children with T1D under the age of 18, were recruited and divided into a rural or urban focus group of six participants. Focus groups were video- recorded, transcribed verbatim, and thematically analyzed. Collaboration with a Caregiver Advisory Committee of three mothers of children with T1D offered invaluable insight, enhancing the quality, relevance, and impact of the research. **Results:** We identified six common themes between the two groups: (a) increase access to mental health services, (b) offer ongoing education for diabetes management, (c) improve respite support, (d) increase T1D financial aid, (e) augment school support, and (f) facilitate social interaction. Mothers in both groups had similar support needs, with the exception that mothers in rural areas required more financial considerations for travel to the urban centre for support and greater access to specialized T1D care. All mothers emphasized access to affordable counselling, ongoing and tailored diabetes education, and trained respite support to alleviate physical and mental exhaustion. They also required financial aid to minimize the costs of diabetes care, trained aides in schools, and

organized community events to connect with other families managing childhood T1D.

Conclusion: The study highlights the importance of comprehensive supports that address the multifaceted needs of mothers caring for children with T1D. These supports are essential for improving the quality of life for mothers and their children with T1D.

Exploring the Support Needs of Mothers of Children With Type 1 Diabetes in Northern Alberta: A Qualitative Descriptive Analysis

Type 1 diabetes (T1D), accounting for 10% of all diabetes cases (Hex et al., 2012; Norris et al., 2020; Saeedi et al., 2019), is a chronic condition that profoundly affects the lives of those diagnosed and their family caregivers. It necessitates a rigorous daily regimen of blood glucose monitoring, physical activity, insulin administration, and dietary management and adjustments to maintain optimal glycemic control and prevent health complications (International Diabetes Federation, 2017). The management of these care tasks is largely dependent on parental involvement, and caregiving responsibilities for children frequently exhibit gendered patterns, with women often assuming primary caregiving roles within the family unit (Calasanti & Kiecolt, 2012; Ghosh et al., 2020). Research indicates that for children with T1D, mothers often bear the responsibility of managing this complex condition and play a crucial role in coordinating its various aspects (Meleski, 2002; Wysocki & Gavin, 2006).

The caregiving journey for mothers is inherently demanding, requiring a delicate balance between medical management and addressing the psychosocial, physical, practical, and financial implications of this chronic condition for themselves and their children. In fact, a study by Streisand et al. (2010) found that mothers commonly experience grief and loss, mourning the future they had envisioned for their child and themselves before the diagnosis. The unpredictable nature of blood glucose fluctuations and the associated implications on daily activities contribute to psychological outcomes such as heightened levels of depression, stress, and anxiety, especially compared to mothers of healthy children (Hilliard et al., 2015; Rechenberg et al., 2017). Glucose fluctuations during growth spurts, illnesses, or the child's developmental transitions, such as puberty, may exacerbate this stress. For instance, caregivers of teenagers with

T1D report anxiety over their children experimenting with alcohol and making appropriate dietary choices when among friends or at social gatherings (Silverstein et al., 2005).

Managing T1D requires careful daily routines and commitment, which may limit or modify familial, professional, or personal responsibilities for mothers (Sullivan-Bolyai et al., 2002). Mothers may experience limitations on career advancement opportunities, conflict over T1D management with their spouse, or altered quality of sleep due to the demands of nighttime glucose monitoring (Keklik et al., 2020; Macaulay et al., 2020; Monaghan et al., 2015). Mothers also report social isolation due to the demands of caregiving. The need to prioritize their child's health can limit their ability to engage in social activities and maintain relationships (Hatton et al., 1995; Pierce et al., 2017; Sullivan-Bolyai et al., 2003). This isolation can be compounded by a lack of understanding from friends and family about the complexities of managing T1D. Smaldone and Ritholz (2011) discovered that a lack of social connection exacerbates feelings of loneliness and reduces access to informal maternal support networks. Furthermore, the financial strain of diabetes management is another significant challenge caregivers face. The direct cost of diabetes care, such as medical supplies, medications, and health care services, and indirect costs, such as missed workdays due to medical appointments, can be significant (Eshtehardi et al., 2021). This economic burden can be particularly challenging for single-parent households or families with limited financial resources or health insurance (Rankin et al., 2016).

Despite the various psychological, physical, social, and financial implications involved in caregiving for a child with T1D, little is known about the support needs of mothers as primary caregivers. In fact, mothers often report feeling unsupported by health care providers, friends, and family who may not fully understand the day-to-day realities of managing T1D for a child (Kimbell et al., 2021; Kobos & Imiela, 2015). The complexities of T1D management and evolving treatment modalities, including emerging technologies, necessitate a comprehensive understanding of the support needs that lead to effective caregiving.

This knowledge is especially valuable from a Canadian context, where the prevalence of T1D among children has been rising, with recent estimates indicating that over 33,000 Canadian children under the age of 18 are living with the disease (Canadian Diabetes Association, 2022). Canada is positioned sixth among the top 10 nations with the greatest incidence of T1D under the age of 15 (Patterson et al., 2014). Despite this growing prevalence, there is a notable gap in the literature regarding the specific support needs of mothers who are primary caregivers to children with T1D in the Canadian context. This study aimed to address the research gap by examining the support needs of maternal caregivers of children with T1D in northern Alberta, considering both rural and urban perspectives. The inclusion of participants from urban and rural areas aimed to ensure a diverse range of perspectives, experiences, and needs from across northern Alberta. For instance, geographically, specialized support for chronic conditions tends to be more limited in rural areas (Caldwell et al., 2016; Dewan & Cohen, 2013), potentially creating different needs compared to urban residents. Additionally, this inclusive approach supports recruitment efforts given the limited number of children with T1D overall. Understanding these needs is essential for developing effective support systems and interventions to equip mothers with resources to alleviate the burdens they face, navigate the challenges associated with their child's condition, and improve the overall quality of life for them and their children.

Methods

Study Design

We used a qualitative descriptive (QD) approach to explore the maternal support needs of mothers caring for children with T1D in northern Alberta. Unlike more interpretative or theoretical qualitative methods, QD emphasizes the straightforward and literal representation of data. The aim of this approach is to provide a rich and comprehensive summary of participants' experiences using their own words (Bradshaw et al., 2017; Neergaard et al., 2009; Sullivan-Bolyai et al., 2003). It is particularly useful for many research questions in health care because it can "help to focus on the experiences of patients, relatives . . . and their views on the organization of the health care system" (Neergaard et al., 2009, p. 4). Furthermore, central to QD studies in health care is the concept of "learning from participants and their descriptions and using this knowledge to influence interventions" (Bradshaw et al., 2017, p. 3). This attribute of a QD research design aligned with the purpose of this study, which was to understand the support needs of mothers. This study was approved by the University of Alberta Health Ethics Review Board (Pro00104580).

Study Setting

Participants were recruited from northern Alberta. Situated in western Canada, northern Alberta encompasses all communities north of Edmonton, including the city itself—a major urban centre with a population of approximately 1 million (Statistics Canada, 2022). Northern Alberta is known for its expansive, sparsely populated terrain and diverse population, including Indigenous communities such as the Cree, Dene, and Métis. Health care resource availability varies across the region, with families in remote and rural areas often experiencing limited access to specialized pediatric diabetes care. Conversely, residents of Edmonton have direct access to the Stollery Children's Hospital and the Pediatric Diabetes Education Centre (PDEC). The PDEC provides support to individuals with diabetes and their families in the form of assessment, education, emergency telephone support, treatment, referrals to other health care providers, and ongoing follow-up for children $\leq$ 18 years with diabetes. Ongoing follow-up appointments are offered at least twice per year, along with continuous telephone support for families to assist with insulin adjustments and therapy changes. Additional services include social work support, nutrition education, referrals to other specialists as needed, and insulin pump therapy coordination through provincial programs. This comprehensive approach aims to provide medical management, education, and psychosocial support for children with diabetes and their families (Alberta Health Services, n.d.). Rural residents also contend with harsh winter conditions lasting 5–6 months annually, potentially making travel to the PDEC for diabetes management more challenging.

Participant Inclusion and Exclusion Criteria

Our inclusion criteria included mothers caring for a child with a T1D diagnosis for at least 1 year, who were living in rural or urban areas of northern Alberta, and who were able to understand and participate in the study in English. As long as the child with T1D was under 18 years of age, the mother was eligible to participate, allowing for a broad understanding of experiences over various childhood developmental ages. This decision also improved the likelihood of recruiting an adequate number of participants considering the limited number of children with T1D. We set a 1-year minimum after a T1D diagnosis to allow participants time to gain sufficient experience to express their support needs. Mothers of children with any additional health comorbidities were excluded. It would be challenging to differentiate between the effects of other health conditions and the distinct support requirements in caring for a child with T1D compared to a child with concurrent medical conditions. For instance, children with T1D are at a higher risk of developing an autoimmune condition like celiac disease, which requires further dietary adjustments such as a gluten-free diet. Some gluten-free foods may contain higher glycemic indexes, influencing optimal T1D glycemic targets. About 5%–10% of children with T1D have celiac disease, compared to 0.5% of the general population (Camarca et al., 2012).

Participant Recruitment and Sampling Strategy

We used convenience sampling to recruit mothers of children diagnosed with T1D. A convenience sampling strategy is useful when the target population meets practical criteria such as geographical proximity (Etikan et al., 2016); in this case, it was at the PDEC in Edmonton, where the participants accessed specialized health services. Annually, the PDEC serves approximately 1,050 individuals from northern Alberta. To find participants, a recruitment poster was advertised on the Edmonton T1D Facebook pages and on the PDEC bulletin board.

Mothers interested in participating in the study contacted the lead researcher (TA) by email or telephone, at which time TA screened each potential participant to ensure that inclusion and exclusion criteria were met. A 20- to 30-minute follow-up Zoom meeting was scheduled with eligible participants to provide a detailed description of the study, confirm interest, answer questions, review confidentiality measures, and discuss scheduling participation in the study. All interested mothers provided written informed consent to participate during the meeting. Of the 12 mothers who participated in this study, five had participated in an earlier qualitative study we conducted on the maternal experiences of caring for a child with T1D. Both studies were advertised simultaneously, and these five individuals had expressed interest in participating in both studies.

Caregiver Advisory Committee

TA collaboratively worked with three mothers of children with T1D as caregiver advisory members to carry out this study. Potential volunteer advisory members were identified by the PDEC, and these three mothers met the same inclusion and exclusion criteria as the study participants. All three mothers had a postsecondary education, and two were employed in the health care field as nurses. TA initially conversed with each advisory member over a Zoom call to orient them to the study, answer questions, outline roles and responsibilities, understand their interests, and obtain informed consent. During the study period, seven meetings, lasting 75–180 minutes each, were held on an as-needed basis over Zoom. Advisory members offered valuable insight and enhanced the credibility of this study by assisting with the development of our data collection tools, providing feedback on the coding framework and the themes generated, and serving as cofacilitators during the focus groups. Utilizing a caregiver engagement approach is valuable because the experiences, input, and suggestions of advisory members enhance the quality, relevance, and impact of the research. Involving these stakeholders in research allows for the examination of issues and the integration of knowledge from different perspectives and points of view (Silka et al., 2013).

Data Collection

After obtaining informed consent, all participants completed an online demographic questionnaire (see Appendix A). The purpose of this questionnaire was to provide information on the diversity of mothers participating in the study and to describe the population for transferability of findings. The five mothers who had participated in our earlier study had already completed this demographic questionnaire and were exempt from completing it again.

It is recommended that a focus group involves a minimum of four and a maximum of eight participants (Kitzinger, 1995; Stewart et al., 2007). Following about 5 months of recruiting, we conducted two focus groups of six participants each. After conducting the two focus groups, no new information was emerging, so we determined that we had reached data saturation. Consequently, we concluded the recruitment for additional focus groups. We followed Bradshaw and colleague’s (2017) rationale that “an adequate sample size is one that sufficiently answers the research question” (p. 4) and Sandelowski’s (1995) suggestion that qualitative sample sizes should be large enough to allow the unfolding of a “new and richly textured understanding” (p. 183) of the phenomenon under study, but small enough so that the “deep, case-oriented analysis” (p. 183) of qualitative data is not excluded.

Focus groups as a data collection method had several advantages. It stimulated conversation among participants in a relatively informal atmosphere, encouraging discussion about underlying issues related to support needs common and unique to the lives of mothers of children with T1D. The group setting fostered synergy, creativity, and idea generation. Participants could comment on one another’s thoughts, leading to the emergence of new ideas or perspectives that may not have emerged in individual interviews. Focus group discussions also provided participants with an opportunity to connect with and find support in one another. Through the group discussions, participants gained comfort in the knowledge that other mothers were facing similar experiences and support needs (Kitzinger, 1995; Krueger & Casey, 2014; Stewart et al., 2007).

The participants were separated into two focus groups based on whether they lived in rural or urban areas. The decision was based on the assumption that access to supports might differ between urban and rural areas. This is because the Stollery Children’s Hospital, a significant support for children with T1D and their parents, is located in Edmonton, an urban area. We thought that by separating participants based on this criterion, they could relate to one another’s experiences and have more in-depth discussions about their support needs. Two separate video-recorded focus groups, each lasting approximately 150 minutes, were held over Zoom in May 2022. The Zoom platform allowed us to conveniently connect with mothers who were geographically dispersed during the COVID-19 pandemic. Prior to starting each focus group, we discussed directions for engagement, the importance of maintaining confidentiality, and how to manage emotional safety.

To steer our discussion during the focus groups, we used a semistructured interview guide (see Appendix B) developed by the team lead in collaboration with the Caregiver Advisory Committee. The urban focus group comprised six mothers residing in Edmonton, Alberta. The lead researcher (TA) and advisory committee members led the focus group discussions. The rural focus group comprised six mothers living in rural northern Alberta; it was cofacilitated by TA and an advisory committee member (MM), a nurse living in urban Alberta. To uphold the privacy of participants and to avoid any potential conflict of interest, another advisory group member (VB), who was a nurse in a rural community, was specifically asked to cofacilitate the urban group. Separate debriefing meetings were held with each cofacilitator after the focus group sessions.

Data Analysis

All focus group conversations were digitally recorded, transcribed verbatim, and verified by TA for accuracy. NVivo 12 was used for data management, including documentation of all research decisions and data analysis. Following Braun and Clarke’s (2006) thematic data analysis framework, TA coded and analyzed the data. TA deeply engaged with the data by repeatedly listening to the audio recordings and thoroughly rereading the two focus group transcripts. First, the urban and rural data were analyzed individually, and codes were separately developed from each focus group transcript. After generating initial codes for each group, an iterative refinement process ensued, where codes were adjusted by collapsing overlapping ones and separating those addressing distinct ideas. Next, the codes for the urban and rural groups were compared for similarities and differences and systematically organized and refined into clusters representing similar ideas between the two groups. Ultimately, this process led to six themes that encapsulate the key findings with nuanced differences derived from the data for both groups. The advisory committee members were consulted during the data analysis process. Through a series of group and one-on-one meetings, they provided feedback and insights on emerging themes.

Findings

Characteristics of the Participants

We had six participants in each focus group (see Table 4.1). In both groups, five participants identified as being White and one individual identified as Indigenous. English was the primary language for all participants. Each participant had only one child diagnosed with T1D, whose average age was 6.7 ± 2.2 in the urban group and 9.3 ± 3.4 in the rural group at the time of participation (see Table 4.2). In both groups, three children were male (50%) and three were female (50%). Five urban mothers were married/common law, and one mother was separated but not divorced. All rural mothers identified as being married or in a common law union. All participants were employed and had completed at least a high school education, with the majority of mothers having additional training or education after high school (100% in the urban group and 83% in the rural group). The average participant age was 37.3 ± 6.3 for the urban focus group and 38.7 ± 5.71 for the rural focus group.

Table 4.1

Demographic Characteristics of Participants

Participant characteristics	Urban focus group		Rural focus group	
	N	%	*n*	%
Marital status				
Engaged	0	0.0%	0	0.0%
Married/common law	5	83.0%	6	100.0%
Separated but not divorced	1	17.0%	0	0.0%
Divorced	0	0.0%	0	0.0%
Widowed	0	0.0%	0	0.0%
Number of children under 18				
One child	3	50.0%	1	17.0%
Two children	1	17.0%	4	67.0%
Three children	2	33.0%	0	0.0%
Four children	0	0.0%	1	17.0%
Education				
Less than high school	0	0.0%	0	0.0%
High school diploma or equivalent	0	0.0%	1	17.0%
Registered trades or apprenticeship certificate/diploma	0	0.0%	1	17.0%
College, cégep, or other nonuniversity diploma	2	33.0%	3	50.0%
Undergraduate degree	3	50.0%	1	17.0%
Advanced degree (e.g., MD, master’s, doctorate, professional degree)	1	17.0%	0	0.0%
Employment status				
Unemployed but seeking work	0	0.0%	0	0.0%
Stay-at-home parent	2	33.0%	0	0.0%
Self-employed (part-time)	1	17.0%	0	0.0%

Participant characteristics	Urban focus group *N*	%	Rural focus group *n*	%
Self-employed (full-time)	0	0.0%	1	17.0%
Part-time employee	0	0.0%	0	0.0%
Full-time employee	3	50.0%	5	83.0%
Racial, ethnic, and cultural background				
White	5	83.0%	5	83.0%
Aboriginal or Indigenous (First Nations, Métis, or Inuit)	1	17.0%	1	17.0%
Annual household income				
$0 to $29,999	0	0.0%	0	0.0%
$30,000 to $59,999	1	17.0%	0	0.0%
$60,000 to $89,999	0	0.0%	0	0.0%
$90,000 to $119,999	2	33.0%	1	17.0%
$120,000 to $149,999	1	17.0%	3	50.0%
$150,000 or more	2	33.0%	2	33.0%

Note. *N* = 12. Percentages have been rounded to the nearest whole number.

Table 4.2

Demographic Characteristics of the Participants' Children With T1D

	Urban focus group			Rural focus group		
Children's characteristics	*M* +/- *SD*	*n*	%	*M* +/- *SD*	*n*	%
Age (yrs)	6.7 ± 2.2			9.3 ± 3.4		
Sex						
Male		3	50.0%		3	50.0%
Female		3	50.0%		3	50.0%
Age (yrs) at diagnosis	3.8 ± 2.5			5.1 ± 2.7		

Note. *N* = 12.

Six themes emerged from the two focus groups held with mothers in this study: (a) increase access to mental health services, (b) offer ongoing education for diabetes management, (c) improve respite support, (d) increase T1D financial aid, (e) augment school support, and (f) facilitate social interaction. We present each in turn with representative participant quotes, lightly edited for readability. To protect the participants' identities, we have used pseudonyms in place of their real names. Table 4.3 provides urban and rural participants' pseudonyms and the age and sex of their children.

Table 4.3

Participant Pseudonyms, Child Age, and Child Sex

Pseudonym	Age (years) of child at time of interview	Sex of child
Urban focus group		
Gayle	3	Female
Connie	5	Male
Megan	7	Male
Kim	9	Female
Sara	9	Female
Dayna	7	Male
Rural focus group		
Jackie	12	Male
Lynne	7	Male
Naomi	6	Male
Amber	14	Male
Ashley	6	Female
Valarie	11	Male

Theme 1: Increase Access to Mental Health Services

Caring for a child with T1D can be emotionally taxing, leading to stress, anxiety, and low mood. Mothers in both focus groups highlighted the importance of access to ongoing counselling services as an essential support need as they transitioned through various stages of caregiving and coping with their child's diagnosis. For instance, Lynne, in the rural group, explained:

> There's a huge emotional toll of knowing that your child has an extremely serious disease that's never going away. And I think the adjustment for me was really hard, and I didn't want to scare my son. I cried in the shower a lot. So, you know, therapy, and some kind of emotional support, I think is so huge.

Mothers in both groups communicated that they believed that offering affordable therapy for mothers of children with T1D is simply not a priority in the health system. They expressed frustration over the lack of support. A mother of a 3-year-old girl shared:

> Therapy is just so important. I'm a single mom, so it's pretty much just me and my daughter 90% of the time. And I can remember, I literally said to the Stollery [Children's Hospital] and to her doctors that I'm on the edge of a nervous breakdown. Like I can't do this anymore. And there was no support for me. I finally was able to get on a wait list to get an affordable therapist, which has really helped. But you know, it shouldn't have been such a struggle for me to have to do it myself, then to have someone who can be like, "Okay, this mom and this child are not going to be okay. We need to help them and support them." (Gayle—urban)

The health care system may not prioritize access to therapy due to a lack of awareness of its need. In agreement with Gayle, another mother in the same group added that the emotional challenges of mothers as caregivers are not recognized enough:

> This is an animal completely unto itself. The sleepless nights, the fear that, I don't know, you're never more than an hour away from a crisis low or a couple hours from DK [diabetic ketoacidosis]. Like, that's a hard way to live. And so, I think our emotional needs are huge and invisible because I think most of us look very competent cuz we have to be, right? You have to be competent and manage your child's needs, and we just do, but I think it's really hard. So, I vote too for therapy. (Dayna—urban)

Some participants in the rural group mentioned that access to therapy was an important source of support for the entire family. Lynne, a mother of a 7-year-old boy, added that in addition to individual counselling, family counselling or couples counselling should also be an accessible option. She explained that T1D management strained her relationship with her partner, and she wondered about the impact of the diagnosis on her other children. She explained:

> It puts such an incredible strain on any relationship, whether it's solid going into it or somewhat fractured already. Also, the relationships with siblings or on other children. It's another perspective, but I think support for families all together would be ideal. (Lynne—rural)

Participants in the urban group advocated that their access to and participation in counselling would also benefit their children and was a necessity for being an adept caregiver. They believed that being able to deal with their anxieties and emotions with the help of a professional would enable them to take better care of their children. One mother stated: "I think it's part of caring for the child. It's part of the child's necessary medical needs that we don't come unraveled at the seams. So, somebody should be doing a little more for us" (Megan—urban). A second mother of a 9-year-old girl agreed, sharing the positive impact that therapy has had on her life:

> I started therapy a year ago, and it's like completely changed everything, especially how I managed [my child's] diabetes, how I talked to him about food, you name it. I think that should be readily available to not only just the kids, but us as well. (Sara—urban)

Two mothers in the rural group expressed concerns about factors that made it difficult for them to seek counselling. Specifically, they mentioned that a lack of respite care was a challenge in attending to their needs and scheduling appointments, including counselling sessions. Amber, the mother of a 14-year-old boy from the rural group, explained: "I have a husband that works in road construction. So, half the year, you know, without having someone who's able to help care for [our child], even booking therapy, going to anything scheduled is so hard."

The high cost of counselling and lack of access to health benefits to offset the costs and make counselling more affordable were raised as fundamental concerns in both focus groups. One mother in the rural group stated:

> It [therapy] should be free. Of course, free. You know, in our house, we don't have great benefits. We're lucky we can afford like his [our child's] Dexcom and all of the supplies and everything, but oh my God. And therapy, yeah, free. Should be provided. (Naomi)

In the urban group, Kim, a mother of a 9-year-old girl, similarly explained: "[Counselling] should be available. It should be free and part of the whole caregiving for someone that takes such a toll on the mental stability of the person caring for them."

Theme 2: Offer Ongoing Education for Diabetes Management

When reminiscing about their caregiving experiences, the mothers in both focus groups highlighted improved and ongoing informational support as being a significant priority among the support that they needed. Mothers shared feeling highly anxious, especially during the initial months postdiagnosis, while learning how to make dietary changes, appropriately dosing and administering insulin, learning to use a continuous glucose monitor (CGM) or insulin pump, and adjusting insulin calculations based on factors such as food intake and activity levels. During this time, while they learned how to manage their child's T1D, they found that follow-up and educational support were essential yet lacking. For instance, Naomi in the rural group stated:

> One thing that I was thinking, sending these families home and you know, this is the type of disease that is daily, constant, never ending. Typically, that's dealt with by a doctor. Now we have to be the doctor. And so, they send us home, but I'm just surprised at the lack of follow-up. You know, we follow up on women after they have their baby with postpartum checklists. There's zero mental health support or follow-up for families, and I think it's so necessary for new families, at least with the young ones.

In disbelief at the paucity of education provided to families, and in agreement with Naomi, Valarie, a mother in the rural group of an 11-year-old, stated:

> Yeah. And I just have to circle back to [Naomi], to your comment about how we send parents home with this super potent medication and are like ready, set, go. We need

> somebody to check in, to ask, “How’s this family doing? Do you have any questions? Can we help with offering some guidance?” I think that’s so necessary.

Gayle, in the urban group, similarly explained her needs:

> I just remember the early days just being a blur. I think, for me, what would’ve helped was transition, because you get educated in the hospital and then they just sort of send you out. I would’ve liked someone physically coming to my home, and whether it’s just to pat me on the back, cuz I’m crying or I don’t understand this. [Someone to ask me], “What are you planning for me today? Let’s work you through your everyday life.” I think that would’ve been huge. Like, it’s just so many things that you don’t, you can’t think of in that specific time in the hospital. And I think there needs to be transition support. I think [that] is what would’ve helped me the most because I was numb. Like, how do you process all this change? It’s hard.

Another mother of a 12-year-old boy summarized these experiences by saying: “I think what we do terrible in health care in general is the transition periods. I feel like it’s like, give the information and then there is nothing to like bridge the transitions” (Jackie—rural).

In addition to follow-up support and check-ins to ensure they felt adept to care for their newly diagnosed children, mothers also mentioned the difficulty of not having ongoing access to a health line or a health professional to which they could direct their T1D-related questions. They said that such a service would be another way to support their informational needs. For example, Megan explained:

> For me, having someone to ask questions of has been huge, which sort of bridges the teaching sessions that we’ve had at the hospital. And then, . . . you’re sitting there in front of your kid and it’s 11:00 p.m. and something is going crazy with their pump or whatever, and yeah, I think it’s really, really difficult, at least for us in the beginning. It’s been really, really hard to figure out what the right thing is to do when you’re on the fly.

Mothers in the rural focus group especially highlighted how an informational hotline could also be helpful for assistance with navigating technology-related questions. For example, a mother of a 6-year-old girl shared:

> So, one of the supports I wish that we had had was somebody who was more literate in the technology and more literate in the devices that can support [us]: apps, recording apps, glucometers in our Bluetooth—like, we were told nothing about that stuff. And I really felt like I had to dig for all that information, and that bothered me. (Ashley—rural)

Valarie, in the rural group, echoed that idea:

> From a support perspective, like having that medical support [would be helpful], but also having somebody that knows the tech so I can maximize using it and without it always being like, “Oh, I’ve got to call the company,” or spending hours trying to figure it out. Right? Having someone show me would be ideal.

In the absence of this support structure, some mothers relied on online communities such as Facebook groups to obtain the information that they needed. Mothers expressed gratitude for these groups, and seeing others post questions online reassured them that they were not the only ones struggling. However, many participants warned about the perils of receiving inaccurate information. Some also mentioned that reading online posts made them anxious about future challenges they were previously unaware of. A mother of a 5-year-old boy in the urban group explained:

> I think, if you’re lucky, you have wise, knowledgeable, informal networks to coach you, but that’s an awfully a big gamble, right? Like, you’ve got to hope that the people are giving you sage advice. But, you know, we need something like a constantly staffed nurse line for diabetic families, right? Like, they understand the disease, they know how pumps work. They can get in touch with an endocrinologist. So, we need something more specialized. (Connie)

Connie further suggested that an online space moderated by health professionals would be helpful, so that “you knew that the advice you were being given was, in fact, good advice that [you could] . . . apply to your own situation.” As a similar solution, another mother in the urban group suggested the following:

> If there was just something that you could log onto when you make a mistake, and you don’t know what to do, like you can actually in real time have a quick chat with somebody, like a direct line to a doctor. . . . [The doctor could say], “No, it’s going to be okay, try this,” whatever. And then it could be worldwide, right? Like, it doesn’t have to be just in Edmonton. (Gayle)

When thinking about the type and quality of informational support, mothers specified that it not only needed to be delivered by T1D experts but also catered to the unique needs of each family. One mother, for instance, shared: “I was never really taught what kind of foods, what kind of activities would need an extended bolus, how to do that. And it's so variable. Like, every child needs something different or every diabetic is something different" (Amber—rural). In the urban group, the mother of a 7-year-old boy suggested:

> Maybe we can get some ongoing information that's sent out, or videos. Yeah. I mean, I think videos would be fantastic. That's such a good idea because you could make a series on all kinds of different topics, right? Puberty, alcohol, long-term health consequences, all of these things, and let parents go to a website where they watch what they want, when they want. And I come back [to my health care team] with questions, right? (Megan)

When discussing informational needs and family-centered T1D supports, mothers in the rural group emphasized that resources tailored to families were even more limited in their regions. In addition to informational needs and follow-up support, they stressed their need for overall better medical intervention and access to T1D experts. The participants stressed the lack of clinical support and access to diabetes care specialists. Families in rural Alberta receive specialized care from the PDEC Stollery in Edmonton. However, referral and access to the PDEC can take up to 1 year. Families in rural regions, therefore, rely on their general practitioners and local hospitals for support. As a result, mothers expressed feeling anxious and doubtful that their children's T1D was being appropriately monitored and controlled in the meantime. For example, in the rural group, Ashley shared:

> It scared the life out of me when they said that we had to see our family doctor for type 1. Not that I want to judge her. She's a great doctor, but still, I mean, there's specialists for this, right? We shouldn't have to see just a regular family doctor who's not even specifically a pediatrician.

Another mother agreed, stating: "Basically, we need an endo [endocrinologist] up here, or more pediatricians, from our experience. Someone who knows a little bit more, that can support us so we don't have to wait so freaking long to talk to [a specialist]" (Lynne—rural).

Mothers residing in rural regions faced additional challenges around access to clinical care compared to mothers in the urban group. Once admitted to the PDEC, travelling to the

Stollery resulted in additional hardships for some mothers, including driving in harsh weather conditions, bearing financial costs due to the travel involved, or having to spend the night at a hotel depending on the timing of the appointment and the travel time to consider.

Theme 3: Improve Respite Support

Participants in the focus groups explained that the constant management involved in T1D care resulted in minimal time for themselves, for social activities, and for their relationships or friendships. For example, Amber in the rural group shared:

> I would just say that that [it] would've been very helpful to have some kind of support cuz we just didn't go out, like ever. From [our son being] age 6 till, I don't know, like 12, we just never went out, or I would go out or then my husband would go out with one of his friends, . . . but we just never left together. We didn't have the support. So yeah, it's tough. And that definitely impacts everybody's mental health when nobody can get a break.

Participants deemed that the mental and physical exhaustion caused by their caregiving duties could be alleviated with respite care. However, whereas in some households children spend time with grandparents and extended family members, mothers in the focus groups expressed experiencing several challenges with this type of support due to the complex care needs of their children. In the urban focus group, Dayna explained:

> Getting that support to be able to train the other staff, and to train family, to feel comfortable enough. Like, we don't even have someone to watch my daughter overnight, you know, no one's comfortable enough to take on that role. So having that training support would be a really big benefit.

The mothers attributed the reluctance and discomfort of extended family members to their fear stemming from lack of knowledge and confidence about T1D management when asked to provide respite care. For instance, in the rural group, Lynne shared,

> Most of my family refuses to help us with [our child] cuz they're absolutely a hundred percent terrified of taking care of him. The only person that knows how to take care of [him] is my mom, fully, and that is overnight. Other than that, we don't have anyone.

Accordingly, participants in both groups emphasized the importance of increased access to T1D management training opportunities. They presumed that family members, in addition to professional caretakers, would benefit from formal training opportunities and that providing such opportunities would increase the number of individuals available for respite support. That said, they cautioned that the process needed to be well planned out. One mother explained:

> It isn't enough to just have a break or respite, like it needs to be safe respite. . . . Our anxiety and worries, which are appropriate and reasonable, need to be addressed, as well as just the physical safety of the child. (Connie—urban)

Another mother added that the complex needs of all parties needed to be considered and addressed:

> There's two parts to having family help, right? There's their willingness to learn and to have the courage to try, and then there needs to be our confidence that they're safe. And then if you have more technology, if you have pumps and things like that, there are whole new sets of problems that can arise. (Megan—urban)

Kim, in the urban group, explained that the existing training programs available to grandparents were not comprehensive enough and even exacerbated caretaking fears and anxiety:

> We actually were offered a program through the Stollery here that was for caregivers, and we sent all the grandparents to it. We were very hopeful coming out of that, that everyone would feel comfortable. But it was so very basic that . . . some of the more scary talking points actually made them more nervous about, you know, participating. We have one grandparent set that did take it on a little bit and has helped with day-to-day stuff and the one set that wouldn't feel comfortable.

To remedy this situation, participants suggested the development of certifications for T1D caregivers and access to a list of certified caregivers they could share in the community to offer babysitting services and respite relief.

Theme 4: Increase T1D Financial Aid

Even though most of the study participants were upper middle class and could afford their child's T1D care, they still expressed a need for various financial supports. Mothers advocated for more financial subsidies and supports to offset having to take caregiving sick days and being subjected to the associated wage loss, buying medical supplies and technology, and paying for the cost of groceries and travel to appointments.

Mothers raised concerns about the high costs of technology, such as the CGM, and the regularly needed medical supplies that are imperative for caring for their children. These costs were especially burdensome for families without good access to health benefits. One mother summarized her family's situation:

> Yeah, this is an expensive disease. Our son has a Dexcom. We don't have coverage. We pay out of pocket; it's $300 a month. There's this new plan in Alberta, but because of our income level, and we are not wealthy people, we'll only pay $200 a month plus insulin, which we only pay a little bit—plus remover wipes, plus skin tack, plus cream, plus band aids, plus, plus, plus, plus. It's really expensive. Families need more. I don't know how all families make it. . . . My heart breaks to think of families who have to make choices where they can't have these things. That's so wrong. (Megan—urban)

On the topic of technology affordability, a mother in the rural group shared her experience of trying to get insurance coverage:

> In the beginning, my Sunlife [insurance] plan did not cover Dexcom. I had to write letters to Sunlife. I had to gather information from Dexcom, I had to get letters from the endocrinologist. So, I [had to] fight for coverage for my 2-year-old to have lifesaving technology . . . so we could actually sleep. They have the Alberta pump program, which completely covers you for a pump, so why don't they have something for the Dexcom? You know, it's kind of a similar thing. And I think the Dexcom is a lifesaving device. (Naomi)

Participants acknowledged having access to some monetary support, such as a disability tax credit, yet participants in the rural group especially explained the need for more financial support and consideration around time off work to attend doctors' appointments. Because there are no specialized supports in rural areas, children with T1D must travel to the Stollery PDEC to receive care. Given the distance to the Stollery from rural areas, participants pointed out the cost of gas, potential loss of wages for the longer time they needed off work, and possible hotel costs for overnight stays in Edmonton. Although some mothers mentioned that the option of virtual appointments had the benefit of offsetting travel expenses and reducing the time away from work, in-person visits were sometimes preferable and also required.

Another financial strain that mothers described was the impact that caregiving duties had on their careers and, consequently, their earnings. This concern was mentioned in both focus groups. For example, Dayna in the urban group said, "I've had to change my career path to . . . help [my daughter]." In another example from the urban group, a mother explained that caretaking demands sometimes affected the number of hours she was able to work, which influenced her commission-dependent and contract-based income. Connie, the urban mother of a 5-year-old boy, shared:

> Time away from work [is] another cost that we bear, right? I'm a contractor. If I don't go to work, I don't get paid that day. And when I've had to do appointments like the Stollery, . . . if they happen to want to see me on one of my regular days of work, I just lose, you know, X percentage of my income that week.

Other mothers shared their worries about missing out on long-term opportunities for career advancement and suffering potential salary drawbacks for needing to be present with their children's health demands. For instance, Jackie, in the rural focus group, stated:

> And there's so much that's nebulous, right? How does it look when it's time to consider a promotion or something? They know you've got a sick child; they know you don't show up all the time or, you know, you have to go home from work because your kid has got ketones. Right? Like I've done that. I guess one thing that I can think of is do we create nondiscrimination legislation that we can't be penalized? But honestly, I think a lot of that stuff is pretty toothless.

Another mother in the urban group, Gayle, explained that training in her career of choice did not allow her enough flexibility to care for her daughter's spontaneous and constant needs. As a single mother, she was required to alter her career path when her daughter was diagnosed with T1D, which reduced her income potential. This mother highlighted the importance of creating more flexibility in the workplace.

To alleviate these financial repercussions, participants suggested that there needs to be more awareness around maternal T1D caregiving responsibility and the implications on career and financial factors. For example, one participant in the rural group emphasized:

> I think we should be able to meet the medical needs of our children with an appropriate level of presence but not have it impact our jobs. There needs to be a better understanding of the somewhat more invisible but enormous price tag that we are paying. (Lynne)

Participants also recommended the creation of a subsidy to offset lost working hours. In the urban group, Dayna suggested:

> It would definitely be beneficial to say that if you're on the disability tax credit, then there should be an allotted number of days that you get off. Whether it be two days a month, or you know, something a week, however many it is, you know, based on your disability. We've already applied for this, so why can't we add in another layer to this, of saying, "Okay, so we know there's going to be X number of appointments every year, those you are covered for X amount."

Theme 5: Augment School Support

The mothers in this study maintained that greater support within the school system for themselves and their children was an overlooked issue and a crucial topic to discuss. A primary concern that was raised was a lack of available support to manage their children's T1D within the classrooms. One mother explained:

> They need a knowledgeable adult around them at all times because you've got that window where within 30 minutes you could be in a crisis, and that can be prevented if you have an appropriately trained adult on site who knows how to monitor your child. It's not good enough to have [someone say], I don't know, "Just pop down to the office twice a day to check your blood sugar." (Megan—urban)

Mothers in both groups emphasized the importance of having qualified, trained aides at school. They commented that only medical aides and individuals with specific T1D training should support their children during school hours. Although grateful for educational assistants (EAs) where available, overall, mothers advocated that T1D-informed individuals would best comprehend the complexities of T1D and know how to treat a hypoglycemic or hyperglycemic event.

Some mothers believed that because the severity of T1D is often underestimated, T1D tends to be overlooked for specialized support within schools. They brought awareness to a lack of funding allotted to school aides for children with T1D and the burden of care that is consequently imposed on teachers. They considered it unfair to expect teachers to educate "a room full of children" (Sara—urban) and simultaneously be attentive to the medical needs of the students. They desired more communication with, and awareness and acknowledgement from, their school districts, principals, and educators about the needs of children with T1D. Sara further shared:

> Lots of other kids get a lot of supports when they have needs, and so they should, but again, I think diabetic children are kind of a little invisible. They don't necessarily look like a child who has a special medical need. Right? They walk, they talk, . . . all their normal things. And so, I don't think they get adequate medical responsiveness from the school system, and I think that's wrong.

Participants explained that the lack of support within schools not only put their children's health in jeopardy but also affected their own mental well-being and day-to-day lives as caregivers. For example, the shortage of support aides led to more reliance on mothers to actively manage their children's diabetes during school hours. Many mothers constantly monitored their children's CGMs and sometimes left work to provide medical care for situations they believed could have been handled at school, if only an aide or someone informed about T1D had been on site. Consequently, this left some mothers feeling anxious and obligated to be nearby at all times.

Although some children had the support of a teacher or an EA during a period of their education, and mothers described this as a helpful experience, they clarified that it was not the norm, nor was it a consistent form of support for families to rely on. The mothers whose children had received this support shared that they had intentionally enrolled their children in a French immersion school where a support aide was more readily available, or, by coincidence, their child's EA or teacher had prior exposure to being around someone with T1D. Mothers further explained that EAs were not equally qualified within the school system, and if their child's EA needed to be absent, no substitute EAs were available. This lack of availability and inconsistency led to missed days at school for their children and time off work for them to stay home with their kids. One mother of a 6-year-old boy shared: "We missed a ton of kindergarten because of EAs being out sick, and there's just nobody else to watch my kid. So, we had to miss work and school to accommodate for that" (Naomi—rural).

In addition to wanting medical support in the classroom, mothers in both focus groups emphasized their need for improved communication with teachers and school staff regarding their child's T1D. They asserted that this communication was necessary prior to the start of each school year and throughout their child's academic year. Some mothers had created their own presentations with an individualized care plan (ICP) to circulate via email, but they wanted mandatory meetings to be scheduled with the school staff to review the material. For them, this would indicate that school system personnel understood that T1D is a serious condition.

Theme 6: Facilitate Social Connection

Mothers described their caregiving experience as isolating and explained that their parenting challenges could not be understood by those without a child with T1D. They found comfort and support in meeting and speaking with other mothers with T1D kids. They also found that connecting their children with other kids diagnosed with T1D was beneficial for their children. For instance, Dayna, the mother of a 7-year-old boy in the urban group, shared:

> That almost instant connection that you can have with the parents gives you a really good support. And even doing something like this, you know, feeling like, "Okay, I'm not

> alone in these fears and this anxiety that I'm constantly having," which is really nice, but there isn't a lot of places that we can go to be able to reach out and get that support and get even just that acknowledgement that, hey, we're not alone.

Ashley, in the rural focus group, stated:

> We did some swimming days and some group-like things here in Grande Prairie. It was helpful talking and just sharing. I think that sometimes you don't know what you need until you're talking to somebody else who's going through or has gone through what you have.

Gayle in the urban group described the positive impact that connecting with other families and their children with T1D has had for her child:

> My daughter has never met another kid out in the wild, really, as we like to call it, with diabetes. And when you do randomly run into someone at a spray park who's got a pump on, and you notice the two kids wearing a pump, it's amazing to see the camaraderie that comes with kids.

In addition to describing the benefits mothers gained from social connection with others in the T1D community, a mother in the rural focus group described how being the one to offer support to others was also beneficial for her journey as a caregiver. She stated:

> Sometimes I feel like healing the trauma is trying to help other people to not have to go through like the same level of trauma maybe that you went through. It's almost like a form of reverse therapy by helping other families that are newly diagnosed. I mean, it sucks that we both have kids with it, but I'm glad that we can go through it together in a way. I enjoy being able to help, for sure. (Amber)

When thinking about connecting with other mothers and their children, some participants expressed their preference for in-person meet-ups. A mother in the urban group described her point of view as follows:

> We had tried to do virtual ones [meet-ups], but . . . I don't love this whole virtual world. I want to sit next to somebody, you know, over a cup of coffee and . . . really spell out . . . the hard things that you go through in a less weird robot techy way. (Kim)

In agreement, Megan in the urban group expressed:

> Going to the internet is . . . not as real, for me. It doesn't feel like a close enough emotional connection to feel supported to kind of go that way. It's just how I'm wired, I guess, but there's not a whole lot [of activities or events] in real life.

Despite the benefits that social interaction can provide to mothers and their children with T1D, participants pointed out the dearth of organized events in their communities and expressed not knowing where to go for them. A few participants recalled organizing a few social activities amongst themselves over the years, but they conveyed that it was an unreasonably big task to plan for regularly. The mother of an 11-year-old boy explained:

> I think we need to go back to the grassroots of community support. But it's the blind leading the blind. It was always something that was planned by someone offering their own free time to put something together. And so, who takes initiative for that and who takes responsibility for organizing and the burnout. (Valarie—rural)

Discussion

Drawing upon focus group data, this study identifies the support needs of mothers of children with T1D in rural and urban northern Alberta. Mothers described managing their child's T1D as an all-encompassing caregiving experience that requires various resources and supports, including access to mental health services, improved informational supports, respite care, financial assistance, T1D support within the school system, and social connections.

Access to Mental Health Support

We found that prioritizing accessible, affordable mental health support is essential for improving the quality of life and the coping skills of mothers. Participants in both focus groups highlighted their need for ongoing access to affordable counselling to better navigate their emotional challenges with their child's diagnosis. Few participants in our study had extended health benefits to cover counselling services, and those with access to it found that only a small amount was allocated to therapy support. Although there is a lack of direct research on the pre- and post-intervention benefits of counselling for caregivers of children with T1D, counselling interventions have been shown to be beneficial for caregivers of children with chronic conditions. Counselling can offer practical self-care skills and coping strategies for dealing with stress, grief, anger, feelings of isolation, and anxiety associated with the diagnosis or with managing caregiving and work–life balance (Cuijpers et al., 2015; Mahmoud et al., 2023). Mothers in this study who had received therapy acknowledged feeling more capable of managing their child's diabetes and noticed improved relationship satisfaction with their children as a result of being more emotionally balanced. A bidirectional impact may take place in caregiving, where the illness impacts the caregiver, and the stress of the caregiver influences the child's health-related outcomes (Anderson & White, 2018; Morris, 2012) and can interfere with the parent–child relationship. Given the complexity of T1D, our findings suggest that mothers should be referred to mental health professionals with specialized training and an understanding of caring for an individual with T1D. During follow-up visits, health practitioners can play an important role in identifying mental health deterioration and distress and motivating mothers to attend counselling or support groups.

Having a child with a chronic disease can disrupt normal routines and may require the shifting of responsibilities and roles among family members, creating high levels of stress within family dynamics (Anderson & White, 2018; Meleski, 2002). In fact, the literature on caregiving indicates that a fundamental interpersonal structure in the adaptation of caregiving for a chronically ill child is the family unit (Meleski, 2002). How the family responds to the stress of caregiving is a critical predictor of how individual family members will function and cope (Meleski, 2002; Shapiro et al., 1998). Consequently, family or couples counselling should also be an available resource in addition to individual counselling. Families with a child with T1D would benefit from a subsidized program or an allocation of individual and family counselling sessions each year. These sessions should be offered in person or online to accommodate flexibility and preference.

Informational Supports

The shock and overwhelm mothers feel during the initial period postdiagnosis can make it challenging for them to comprehend the information being given to them. Mothers in both groups expressed a need for ongoing education about T1D and how to manage it. They suggested more scheduled check-ins from a health care professional for several months following the diagnosis and as needed afterwards. These appointments would allow mothers to ask questions and reinforce their knowledge and confidence about T1D management. Our finding is consistent with a recent study by Heike et al. (2022) that investigated ways to reduce caregiver distress among parents of children with T1D across nine pediatric diabetes centres in Germany. Heike et al. found that 78% of parents wanted more diabetes training and felt that it would reduce their distress. Watt (2017) and many other researchers (e.g., Haugstvedt et al., 2011; Kobos & Imiela, 2015) have found that sense of caregiver burden among parents of children with T1D is less associated with demanding daily caregiving routines and more related to concerns about unpredictable sugar levels, potential hypoglycemic episodes, inability to provide adequate and timely care, worry over long-term health complications, and concern about the child's future. Knowledge and mastery of skills required to manage T1D, especially soon after diagnosis, can improve parents' ability to cope with caregiving demands, strengthen confidence, reduce their perception of stress, and thus mitigate caregiver burden (Meleski, 2002; Pierce et al., 2017; Reinhard et al., 2008). These capabilities are critical for the family's overall functioning, and more scheduled check-ins postdiagnosis could help to improve their competence.

Currently, clinical visits with an endocrinologist are scheduled approximately every 3 to 6 months. However, because the provider usually recommends scheduling of follow-up visits, appointments may not align with a patient's or caregiver's needs, as identified in our findings.

Boogerd et al.'s (2015) study on parents' experiences, needs, and preferences in pediatric diabetes found that parents wanted more tailored care with needs-specific information and timing. Similarly, our findings indicate that delivering the best care will necessitate adapting guidelines to accommodate caregivers' and patients' preferences within the clinical setting. Recognizing that informational needs postdiagnosis may vary depending on factors such as the child's age, the duration of the diagnosis, and the family's health literacy, follow-ups from health professionals should be catered to the unique needs of each caregiver and child. Conducting needs assessments can provide insights into a family's informational requirements, facilitating the delivery of targeted and personalized support.

We found that mothers often lean on social media platforms, such as Facebook groups, and on other mothers with T1D children to get answers to questions on topics such as diet, insulin injections, carb counting, or T1D technology. Research has demonstrated that diabetes forums can enhance users' sense of belonging and social support while reducing distress (Balkhi et al., 2014), yet participants in our study also cautioned that advice obtained through these avenues may be inaccurate, leading to medical risks and highlighting the need for more reliable and readily available formal sources of informational support. Mothers described the creation of informational phone or chat lines staffed by medical professionals as an ideal and desired solution. Call takers should have specific and mandatory training about T1D in children. This type of support could reduce medical risks and anxiety among mothers when dealing with unexpected or complicated situations. Ongoing general education should also be offered to caregivers, such as how to create balanced meal plans, manage T1D during school attendance, address T1D and alcohol consumption, or cope with puberty and developmental milestones. This instruction could be offered via a video series on commonly used diabetes websites. Mothers in rural Alberta would especially benefit from such informational supports given the absence of a specific care team or program for supporting children with T1D in rural areas.

Respite Care

Whereas counselling support can offer mothers tools and strategies to cope with their feelings, respite support can provide physical relief (Murphy et al., 2021). The development of organized respite care programs is needed in rural and urban Alberta to give mothers access to specially trained and knowledgeable individuals in managing T1D. We found that some mothers sacrificed career advancement, social activities, and alone time with their spouses due to a lack of respite care. Supporting research by Murphy et al. (2021), respite aid would allow mothers to take a break from daily caretaking demands, participate in social functions, practice self-care, and attend to their careers. This relief may be even more necessary for single mothers, as single parenting is associated with increased physical demands, parenting stress, and reduced support (Heike et al., 2022). Respite care for families of children with complex health needs has been found to increase coping, improve quality of life, and reduce stress (Chan & Sigafoos, 2001). This form of support can prevent burnout and increase the mental well-being of mothers. Our findings indicate that extended family members do not always feel comfortable with offering respite relief, and mothers do not trust that family members have sufficient knowledge or training to provide care. Comprehensive training programs for extended family members need to be offered regularly so that mothers can also rely on family for caregiving relief.

Financial Assistance

Financial supports or subsidies beyond what is currently offered in Alberta to offset the costs associated with T1D care, including formal respite support, should be put into place. This assistance will be especially important for families living in rural Alberta. Mothers in both rural and urban Alberta experience economic burdens with the cost of T1D technologies, medical supplies, and the loss of wages due to career shifts or time away from work, yet mothers in rural Alberta experience additional financial repercussions. These additional costs accumulate from travel to the PDEC to receive care. Depending on weather conditions and appointment scheduling, families in rural areas may need to stay overnight and request unpaid time off work, adding to their caregiving expenses.

T1D Support Within the School System

We identified interaction with school systems and teachers as another important part of the caregiving experience for mothers. School staff's attitudes about, reactions to, and knowledge of a child's T1D condition, and their capability to address medical needs (e.g., administering medication), can seriously impact that child's health and school attendance, and thus the caregiver burden (Plisková & Snopek, 2017; Sexson & Madan-Swain, 1995). Support for students with diabetes varies widely across Canadian schools. There are significant differences in the availability of resources and the implementation of policies, even within schools located in the same jurisdiction (Lawrence et al., 2015). Likewise, we found that across northern Alberta, urban and rural, the level of school support offered to children with T1D is inconsistent, with no discernable differences in availability between the two regions.

Founded on the principle of ensuring safety in the classroom, in 2019, Alberta Education introduced an ICP template to be used in schools for children with diabetes. These plans are intended to be collaboratively developed with parents, schools, and health service partners to address daily management needs and emergencies (Alberta Education, 2019). However, participants in our study in both rural and urban regions reported inconsistent use and implementation of these ICPs. Additionally, participants explained that schools do not mandate teachers to undergo training in T1D management, leaving the onus on parents to educate school staff. Some classrooms have EAs or teachers who may show a personal interest in learning about T1D, yet neither group is necessarily medically trained to manage T1D. Consistent with prior research (Streisand & Monaghan, 2014), our findings indicate that insufficient support for fluctuating glucose levels during school hours results in children being sent home, prompting mothers to take time off work to care for their child at home or make school visits. These experiences raise the necessity of schools adopting onsite nurses or EAs with special T1D training and ensuring that teachers with students with T1D in their classes attend mandatory T1D training. Families would also benefit from consistent application of ICPs and regular communication with their children's educators about their children's needs and health statuses. A policy of this nature would create more trust between school staff and families, improve T1D management in the classroom, and reduce mothers' anxiety.

Community Connections

Participants in our study emphasized the importance of social connection with other caregivers of children with T1D as a support need. Community activities offer benefits such as finding comfort in the support and friendship of other mothers caring for a child with T1D, finding or being a peer mentor, and creating an environment for their children to meet. This exchange can help reduce parents' feelings of isolation and increase their self-confidence and knowledge (Boman, 2018; Rankin et al., 2016). Findings by Boman (2018) and others (e.g., Sullivan-Bolyai & Lee, 2011; Thomson et al., 2015) suggest that peer mentors also benefit when they support other parents who have children with T1D. By acting as role models, they feel empowered, gain knowledge, and learn new skills in the process. However, for activities and connection to take place, the initiative and planning depend on mothers themselves, who already have demanding schedules. Regular social events in rural and urban Alberta, organized by community programs with access to resources, volunteers, and funding, could address this need.

Limitations and Strengths

This study adds to the literature by sharing the support experiences and needs of mothers of children with T1D from a Canadian context and drawing on both rural and urban perspectives. For the mothers, discussion with other participants allowed them to feel valued, empowered, and validated in their challenges and triumphs. Participation also created a social platform for them to connect with other mothers, which may serve as a support network. Another strength of this study is that it was developed in collaboration with three caregiver advisors who were mothers of children with T1D. Advisors supported the focus groups as cofacilitators, contributing to meaningful questions and discussions.

The study participants were diverse in age, marital status, their child's age, and diagnosis age. There was also a balanced representation of male and female children with T1D in both groups. However, participants were predominantly English-speaking, upper middle class, and White, with only two individuals identifying as Indigenous. Future research would benefit from exploring the support needs of single mothers, mothers from lower income brackets and more diverse backgrounds, and those with English as a second language, as these factors may uncover additional areas of support needs. Furthermore, although we had a diverse representation of the ages at which children were diagnosed with T1D, only one participant had a teenager presently living with T1D, and only one had a child under the age of 4. Given that developmental factors associated with a child's age may alter specific support needs, future studies are warranted to explore the needs of mothers with toddlers and mothers with teenagers.

Conclusion

In this study, we divided participants into two focus groups, rural and urban, to understand the support needs of mothers in northern Alberta. A noteworthy finding was that mothers generally have uniform support needs regardless of location. Two differences we found were that mothers in rural Alberta require the establishment of a T1D clinical care unit in their region to access endocrinologists, nurses, dietitians, counsellors, and other specialized T1D health care supports. They also have an increased need for financial support to offset expenses related to loss of work and travel to the PDEC in the urban centre for care. Findings underline the importance of ensuring that mothers in rural and urban Alberta have access to resources and supports to manage their child's T1D. These supports include increased access to mental health services, information, and respite care; additional financial aid; uniform policies and protocols in schools; and regular social interaction with other caregivers of children with T1D.

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Appendix 4A: Online Demographic Questionnaire

1. **How old are you?** ______ (Enter value)
2. **What is your current marital status?**
   - ○ Single
   - ○ In a relationship but not cohabitating
   - ○ Engaged
   - ○ Married/common law
   - ○ Separated/ but not divorced
   - ○ Divorced
   - ○ Widowed
3. **How many children do you have under 18?** _______ (Enter value)
4. **How many children do you have with T1D under 18?** ________ (Enter value)
5. **How old is your child with T1D? (If you have more than one child with T1D please list the age for each child.)**

   Child 1: ________ years and ________ months (Enter values)

   Child 2: ________ years and ________ months (Enter values)

   Child 3: ________ years and ________ months (Enter values)
6. **What is the sex of your child with T1D? (If you have more than one child with T1D please list the sex for each child.)**
7. **At what age was your child diagnosed with T1D? (If you have more than one child with T1D please list the exact age of diagnosis for each child in years and months e.g., 4 years and 2 months.)**

   Child 1: ________ years and ________ months (Enter values)

Child 2: ________ years and ________ months (Enter values)

Child 3: ________ years and ________ months (Enter values)

8. **a. How many people live in your household (including yourself)?** ________ (Enter value)

   b. How many of these individuals are under 18 years of age? _____ (Enter value)

9. **What is the highest level of education that you have completed?**

   ○ Less than high school

   ○ High school diploma or equivalent

   ○ Registered trades or apprenticeship certificate/diploma

   ○ College, cégep, or non-university diploma

   ○ Undergraduate degree

   ○ Advanced degree (MD, master's, doctorate, professional degree, etc.)

10. **What is your current employment status?**

    ○ Unemployed but seeking work

    ○ Stay-at-home parent

    ○ Self-employed

        ○ Part-time

        ○ Full-time

    ○ Part-time employee

    ○ Full-time employee

11. What is your total annual household income?

An approximation of your total annual household income before taxes, from all sources, including wages, rent from properties, social security, disability benefits, help from relatives and so on.

○ $0 to $29,999

○ $30,000 to $59,999

○ $60,000 to $89,999

○ $90,000 to $119,999

○ $120,000 to $149,999

○ $150,000 or more

12. Were you born in Canada?

○ Yes

○ No

13. If you answered no to the previous question, in what year did you immigrate to Canada? _______ (Enter value)

b. What country did you immigrate from? ___________

14. Is English the primary language spoken in your home?

○ Yes

○ No

15. If you answered no to the previous question, what is your primary language? ________

16. How would you describe your racial, ethnic, and cultural background?

Please feel free to provide more than one answer if you have several backgrounds.

○ White

- ○ Aboriginal or Indigenous (First Nations, Métis, or Inuit)
- ○ East Asian (Chinese, Japanese, Korean)
- ○ South Asian (e.g., East Indian, Pakistani, Sri Lankan)
- ○ Southeast Asian (e.g., Filipino, Thai, Indonesian, Vietnamese)
- ○ Black or African Canadian
- ○ Latin American
- ○ Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
- ○ Do not know

17. What town/city do you reside in (e.g., Edmonton, Grande Prairie, Leduc)? ________

Appendix 4B: Semistructured Focus Group Guide

Research question: What are the support needs of mothers of children with type 1 diabetes under the age of 18 in northern Alberta?

During the focus groups, mothers will be asked to describe their experiences related to their support needs for caring for their child with T1D.

Preamble: We are interested in learning more about the supports you have received, that would have been helpful, or that you still need as a caregiver for a child with T1D. We want to hear about any type of support you can think of. By support, we mean any information, person, online group, or organization that has helped you, or could have been helpful to you, in some way in your role as a caregiver. This could be support that you directly asked for or were offered; that was in person, by phone, online (like a Facebook group), or printed materials; and that was in the realm of your family and friends, your workplace, the school, or the health care system. Any support or information that you've received, could have used, or still need is relevant. It could be formal or informal.

1. What supports and resources do you need to support your caregiving experience?

What supports/information would have been helpful early on?

What challenges have you faced getting the support you need?

What supports have been helpful?

Who are the people, if any, that you turn to for support as a caregiver? What kind(s) of supports have they provided?

Besides people, which organizations or more formal supports, if any, have offered support, or have you turned to and/or received support from? What kind(s) of supports have they provided?

Did/Do you feel that the support that you have received has been adequate to meet your needs? *(This might come up in Question 5).*

What are your unmet needs for support?

Supports can be delivered in many ways, such as in person, online, through written materials, etc. How could the delivery of supports be improved, if at all (e.g., online instead of in person)?

Is there anything else that you would like to share about your experiences with support as a caregiver for your child with T1D?

Examples of Probes

- What do you mean when you say, "[XXX]?"
- How come/so?
- Does anyone else have a similar/different experience/opinion?
- Before we move on, does anyone else have anything to add?
- Can you tell me more? Can anyone else tell me more about this?
- What else? Can you think of an example to share?
- Is there anything else that we haven't discussed regarding supports?
- Can you tell me what that's like for you?
- [Name], we have yet to hear from you. Do you have anything that you would like to add?

Chapter 5: Conclusion

Managing T1D in children is a challenging responsibility that significantly impacts various aspects of caregivers' lives, especially those of mothers. This requires diverse, appropriate, and long-lasting forms of support (Landolt et al., 2005; Sullivan-Bolyai et al., 2003). Providing such support for these mothers is contingent upon understanding their caregiving experiences. Three studies were conducted as part of this dissertation to explore the experiences and support needs of caregivers of children with T1D.

Chapter 2 presented the first study, a scoping review of the caregiving burden among parents of children with T1D under the age of 18. This study conceptualized caregiver burden by examining the social, financial, spiritual, physical, emotional, and psychological stressors faced by parents caring for a child with diabetes. It provided a comprehensive overview of the literature on caregiver experiences without restricting the focus to children with T1D who fell into a specific age group. Findings from 18 full-text articles that met the inclusion criteria for this scoping review revealed six interrelated themes: (a) experiencing chronic sorrow, (b) assuming responsibility for glucose highs and lows, (c) managing T1D and nighttime sleep disturbances, (d) making career sacrifices and choices to optimize T1D care, (e) navigating social experiences postdiagnosis, and (f) discovering new sources of support through online platforms. This scoping review revealed that parents face numerous challenges in trying to provide optimal diabetes care, including managing their anxiety, grief, work schedules and career ambitions, social activities, and daily routines. Given that caregiver burden is felt continually and in multiple domains, there is a critical need for accessible respite care, including the training of professionals or extended family members to provide safe and reliable respite, which could improve the mental health of parents and support their ability to care for their children's T1D needs. In their search for support, many parents have found comfort and encouragement by connecting with other parents of children with T1D through online communities, forums, and social media platforms.

Given the high and growing prevalence of T1D in Canada (Diabetes Canada, 2021) and the predominant role of mothers as primary caregivers for children with T1D (Lindström et al., 2017), Studies 2 and 3 (Chapters 3 and 4, respectively) focused on mothers' experiences within the Canadian context. To gain deeper insights into the Canadian maternal caregiving experience, in Study 2, 16 mothers from northern Alberta were interviewed about their experiences as caregivers. The themes that emerged from this qualitative descriptive study were (a) "I am the organ": a sense of constant vigilance, (b) accepting a new normal, (c) grief underlying a rollercoaster of emotions, (d) caregiving as an isolating experience, (e) the CGM is a champion, and (f) finding the positives. These themes share many commonalities with the themes found in the scoping review.

First, reaffirming findings from the scoping review, grief emerged as a prevalent theme. It also aligned closely with themes related to making career choices to optimize T1D management and navigating social experiences found in the scoping review, accepting a new normal in confronting social limitations and career sacrifices for mothers. Study 2 likewise found that sleep disturbances and sleep deprivation due to nighttime glucose monitoring were a significant challenge. However, mothers reported that CGMs alleviated this concern. In northern Alberta, participants regarded CGMs as critical resources for support—this finding was not highlighted in the scoping review. Also novel in this study was that mothers identified the positive aspects of caregiving for a child with T1D, such as developing a closer bond with their child. Maintaining a positive mindset and attitude towards caretaking duties reduced negative feelings. The theme of caregiving as an isolating experience corroborated the findings of the scoping review, in which parents described caregiving as an isolating experience and described its challenges as being underestimated by others. To overcome these feelings and the isolation, parents in the scoping review and mothers in Study 2 similarly relied on connecting with T1D peer networks; many caregivers highlighted the importance of finding new supports, friendships, and comfort in connecting with other parents of children with T1D. Studies 1 and 2 also shared the theme of constant vigilance regarding children's well-being and glucose fluctuations, with those caring for younger or newly diagnosed children expressing particularly intense experiences. In both studies, mastery of skills and the quality of training that caregivers perceived that they gained during the early days postdiagnosis helped to reduce anxiety and improve confidence.

Expanding on the experiences of mothers in northern Alberta, Study 3 (presented in Chapter 4) was specifically designed to understand the support needs these mothers require to care effectively for their children with T1D. Recognizing that support needs and access to resources may vary between rural and urban areas, 12 participants were divided into a rural or urban focus group of six participants. The mothers' support needs were summarized into six themes: (a) increase access to mental health services, (b) offer ongoing education for diabetes management, (c) improve respite support, (d) increase T1D financial aid, (e) augment school support, and (f) facilitate social connection. The findings from Study 3 indicate that regardless of location, mothers had similar support needs except for financial support and access to specialized support, which were more emphasized among the rural participants.

In alignment with the experiences detailed in the initial two studies of this dissertation, mothers in the focus groups in the third study underscored the critical need for access to mental health services to address the emotional and psychological burdens related to caregiving, such as anxiety, stress, feelings of loneliness, and grief. They also highlighted the need for more comprehensive education and training and a desire for greater opportunities to connect with other parents facing similar challenges. These findings resonate with two themes identified in the scoping review: navigating social experiences postdiagnosis and discovering new support sources through online platforms. Additionally, many mothers in the third study felt that health care providers could improve their support by tailoring it to the unique needs of each family and offering more consistent follow-ups. These findings were also identified in the scoping review. The significance of these findings is that residents in northern Alberta experience similar challenges to those documented globally in the scoping review. One difference of note is that participants in Study 3 described a need for increased school support and financial aid, yet this topic was not mentioned in the scoping review.

Implications and Recommendations

Based on the results from the three studies comprising this dissertation, 10 broad clinical, policy, and social recommendations are presented to enhance the caregiving experience of mothers of children with T1D. These recommendations were also validated by the Caregiver Advisory Committee and would improve the caregiving experience of mothers in northern Alberta. They may be applicable to other regions with a publicly funded health care system, similar study settings, and participant demographics. Health care providers, policymakers, caregivers of children with T1D, school administrators, staff members at the PDEC, community organizations, and other stakeholders interested in supporting the T1D community could engage in stakeholder dialogues to discuss and prioritize the mobilization of these recommendations. The 10 recommendations are as follows: (a) use a family-centred care approach, (b) enhance postdiagnosis follow-up and emergency support, (c) offer ongoing education for T1D management, (d) integrate psychological assessments for mothers in pediatric diabetes care, (e) provide comprehensive counselling support for caregivers, (f) improve and equalize access to supports for rural and remote dwellers, (g) improve financial assistance and work leave policies,(h) standardize T1D support in Alberta schools, (i) implement a comprehensive respite care program, and (j) cultivate social support and peer connection. I discuss each recommendation in turn.

Recommendation1: Use a Family-Centered Care Approach

Aligned with previous research (Boogerd et al., 2015), our findings indicate the importance of tailored information and supports for caregivers and their children. Recognizing that informational needs postdiagnosis may vary depending on factors such as the child's age, the duration of the diagnosis, and the family's knowledge base, adopting a family-centered care (FCC) approach in T1D management is recommended. As defined by the Institute for Patient- and Family-Centered Care, FCC represents a paradigm shift towards "mutually beneficial partnerships between health care providers, patients, and families in health care planning, delivery, and evaluation" (Kokorelias et al., 2019, p. 2). Implementing FCC models in clinical practice has significant implications for achieving optimal patient outcomes and improving the quality of patient and family experiences (Kokorelias et al., 2019). For example, findings from a recent review (Ispriantari et al., 2023) associated FCC models with improved adherence to diabetes management and better glycemic control.

An FCC intervention may involve discussing and assessing the distribution of tasks at home, pointing out family strengths, and collaboratively finding ways to handle conflicts (Meleski, 2002). FCC can include giving advice during specific transition periods such as developmental milestones. In such cases, caregivers may receive anticipatory guidance on developmental transitions and educational materials about the limitations the chronic condition may impose. Depending on the unique needs or requests of the family, additional interventions during times of transition could include helping with planning medical treatments during school attendance, "giving the child's main caregiver feedback, and acting as a liaison between the family and schools or child care providers" (Meleski, 2002, p. 52). Health care providers should strive to develop care plans similar to those used in education that consider the unique needs, goals, preferences, health literacy, and cultural traditions of each family and child. This personalized approach could significantly empower caregivers by equipping them with the specific knowledge and skills they require (Cheraghi et al., 2015). This understanding could, in turn, mitigate caregiver burden, particularly in the critical postdiagnosis period when families often struggle with readiness and knowledge gaps (Anderson & White, 2018). Findings from Chapter 3, for example, reveal that participants desired more age- and developmental-specific educational supports when managing T1D postdiagnosis.

Recommendation 2: Enhance Postdiagnosis Follow-Up and Emergency Support

Although the PDEC in Edmonton already offers some follow-up support, public health professionals should implement even further robust follow-up protocols immediately after diagnosis, including increasing the number of regular check-ins, providing access to a nurse educator, and offering a phone line to answer any questions between appointments. This approach could be tailored to the specific support needs of each family to alleviate the initial feelings many mothers experience of being "left to their own devices" that were identified in Study 3. The provision of an accessible and dedicated T1D phone line for newly diagnosed children would reduce maternal anxiety when confronted with unfamiliar or challenging diabetes management situations or technical difficulties when using T1D technology. This resource would offer immediate guidance and foster a sense of security for mothers as they gain confidence in navigating the complexities of their child’s T1D care. The PDEC provides a 24/7 phone helpline with access to an on-call endocrinologist or nurse. However, this service is primarily intended for urgent concerns rather than routine or nonemergency questions.

Recommendation 3: Offer Ongoing Education for T1D Management

Our study findings support Diabetes Canada’s clinical practice guidelines (Wherrett et al., 2018), which recommend providing anticipatory guidance and counselling during key developmental transitions (e.g., daycare, school entry). Caregivers would benefit from an educational framework beyond the initial diagnosis and management techniques. This expanded framework should be designed (a) to provide ongoing training and support as children grow and transition through different life stages and (b) to include practical strategies and guidance for navigating school, puberty, social situations, and the eventual transition to adult care. Expertise in T1D management techniques, particularly after diagnosis, can enhance parents’ capacity to handle caregiving responsibilities (Meleski, 2002; Pierce et al., 2017). This increased competence can reduce perceived stress levels and ultimately alleviate the overall burden of caregiving (Meleski, 2002; Pierce et al., 2017).

Participants in our study proposed developing a comprehensive informational how-to video series. This educational content could be made available on widely accessed platforms such as the websites of Diabetes Canada and the Juvenile Diabetes Research Foundation, and health professionals could direct caregivers to this resource. Although general educational videos are available online, content addressing daily caregiving experiences and common questions of mothers needs to be included.

Recommendation 4: Integrate Psychological Assessments for Mothers in Pediatric Diabetes Care

Findings from all three studies indicated that mothers experience various mental health challenges as caregivers. Participants in the focus groups in Study 3 specifically highlighted having benefitted from earlier counselling interventions. This insight underlines the need for health care providers to integrate routine psychological assessments and screenings for mothers into the standard diabetes care protocol for their children. According to the practice guidelines from Diabetes Canada, “Children and adolescents with diabetes, along with their families, should be screened throughout their development for psychological disorders” (Wherrett et al., 2018, p. 133), but it is unclear how well this suggestion is being followed. A more proactive approach could facilitate early detection of potential mental health concerns, including PTSD, depression, anxiety, and caregiver burnout. According to the Canadian Mental Health Association (2018), early diagnosis and intervention of mental health issues are essential for improving outcomes, reducing symptom severity, and preventing more severe, longer-lasting issues from developing.

Recommendation 5: Provide Comprehensive Counselling Support for Caregivers

Confirming previous results, findings presented in Chapters 3 and 4 reveal the significant value of individual and family counselling as a crucial support mechanism for caregivers (Cuijpers et al., 2015). Based on these findings and validation from the Caregiver Advisory Committee, I propose a two-tiered approach to this support:

- Initial postdiagnosis support: Immediately following diagnosis, families should be offered a designated number of complimentary counselling sessions. This initial intervention could address the acute psychological impact of the diagnosis and provide foundational coping strategies.

- Ongoing, affordable, and accessible support: Beyond the initial phase, families should have access to continued counselling services at affordable rates. This ongoing support is essential for addressing evolving challenges as the child grows and the family's needs change. Given the challenges with attending counselling appointments due to lack of respite care, counselling sessions should also be offered virtually.

Recommendation 6: Improve and Equalize Access to Supports for Rural and Remote Dwellers

The literature consistently shows that rural and remote regions often have fewer health care facilities and pediatric specialists compared to urban regions (Dewan & Cohen, 2013). Relatedly, participants from our study in rural Alberta expressed the need for local specialized T1D supports to enhance access to efficient and dedicated services, reducing lengthier commutes to urban centres like the PDEC for specialized treatment. Continued efforts should be made to improve access to specialized care in rural and remote areas, potentially through outreach clinics or the recruitment and incentivization of more specialists to practice in the region. Additionally, wait times for appointments at urban centres should be reviewed to optimize timely access to care for rural patients. Virtual care or telehealth appointments are a potentially effective option when access to in-person care presents challenges. They can alleviate costs with travel and offer efficient support (Diabetes Canada, 2022). At present, the PDEC offers virtual appointments, but some caregivers in rural regions may still prefer in-office visits, as shared by participants in Study 3 of this dissertation.

Recommendation 7: Improve Financial Assistance and Work Leave Policies

Based on the findings from this dissertation, families would benefit from expanded financial support programs to help offset the costs associated with diabetes care, supplies, and equipment. For instance, the CGM was described as a crucial source of support that must remain affordable and accessible (Chapter 4). Special consideration for financial support should be given to families who lack extended health benefits and those residing in rural or remote regions who may incur additional expenses due to the necessity of commuting to urban centres for specialized diabetes care. Additionally, although the Government of Alberta offers various job-protected leaves, including personal and family responsibility leave, they are generally unpaid and do not specifically address the ongoing care needs of children with T1D (Ministry of Jobs, Economy and Trade, n.d.). According to Lahaie et al. (2013), "The social context in which working adult caregivers meet their dual responsibilities . . . will influence whether they can do both successfully" (p. 244). In many jurisdictions, paid sick days attributed to caregiving duties are not covered by employers, and studies have shown that women are less likely to hold jobs providing flexibility and benefits (Lahaie et al., 2013). As such, ensuring that labour laws address and reduce social disparities among working women caregivers is critical. Findings from the scoping review (Chapter 2) revealed that mothers experienced making career sacrifices, such as declining promotions, in order to maintain career flexibility to provide optimal T1D care to their children. Signifying the importance of work culture, research has also found that workplace accommodations and understanding supervisors are necessary for caregivers to remain employed (Versey, 2017; Williams et al., 2016).

I recommend the development and implementation of specific paid leave policies for mothers who need to take time off work to attend to their child's T1D-related appointments and care needs. These policies should include the following features:

- Provide a designated number of paid days off annually, separate from regular sick leave or personal days, specifically for T1D-related care.
- Ensure job protection for parents using this leave.

- Be flexible enough to accommodate both planned appointments and unforeseen T1D-related emergencies.

Recommendation 8: Standardize T1D Support in Alberta Schools

Educational institutions across Alberta should implement a standardized approach to support children with T1D, prioritizing the availability of T1D-trained EAs or school nurses in all schools. Such a measure could significantly contribute to the safety, well-being, and academic success of students with T1D (Lawrence et al., 2015). For example, findings from a study by Drakopoulou and colleagues (2022) revealed that the presence of a school nurse was associated with improved academic achievement, notably fewer diabetes-related absences, and more effective diabetes management among students.

Adding to these findings, our research indicates that standardized school supports could also reduce the psychological burden on mothers and the need for them to make unexpected school visits. For example, in Study 2 (Chapter 3), we found that mothers felt anxious about sending their children to school and even needed to leave work to manage their child's T1D. School supports would also shift primary responsibility for diabetes management away from classroom teachers, allowing them to focus on their core educational duties. In agreement with Diabetes Canada's (2024) position statement on diabetes in schools, we found that it is important for parents and their children that school staff should be clear and confident about their responsibilities and roles in regard to the care of students diagnosed with T1D. Efforts should be made to provide teachers with basic T1D management training through accessible online or in-person courses. Currently, in Alberta, the use of ICPs for students with diabetes is encouraged but not mandatory. Implementing policies that require the use of ICPs would ensure consistent and comprehensive support for students with T1D across all schools (Alberta Education, 2019; Diabetes Canada, 2021).

Recommendation 9: Implement a Comprehensive Respite Care Program

The implementation of a structured respite care program could alleviate burden, reduce stress, and improve the overall quality of life for both mothers and their families (Murphy et al., 2021). The studies in this dissertation reveal that the unavailability and unreliability of respite care hinder caregivers from engaging in social activities, extending work hours, seeking career advancement, and obtaining mental or physical breaks. Based on these findings, a respite care program should include the following aspects:

- Training and certification for respite care providers, including family members, friends, and professional caregivers, to ensure they are competent in managing T1D.
- A network of trained respite care providers that mothers can access when needed. This network could include both volunteer and professional caregivers.
- Flexible respite care options, including in-home care, out-of-home care, and overnight services, to accommodate different family needs and preferences.
- Connections between families to encourage informal respite care arrangements and mutual support.
- Financial assistance to help offset the costs of respite care, particularly for families with limited financial resources.

Recommendation 10: Cultivate Social Support and Peer Connection

Findings from all three studies in this dissertation indicate that caregivers rely on peer support for emotional support, knowledge, connection, and understanding. Social activities, both in person and online, should be regularly organized and promoted to help reduce feelings of isolation among mothers. Connecting with other parents who understand the challenges of raising a child with T1D can provide a sense of community and shared understanding, which is vital for emotional well-being (Lancaster et al., 2022). Peer support programs can be designed to be accessible and inclusive, catering to diverse cultural and socioeconomic backgrounds. This inclusivity would ensure that all families, regardless of their circumstances, could benefit from connecting with others. Programs could be offered in various formats, including in-person meetings, online forums, and virtual support groups, making them accessible to families in rural and remote areas. Health care programs could play a role in facilitating connections between families.

Future Research

This dissertation provides valuable insights into the multifaceted experiences and support needs of mothers managing childhood T1D. The collaboration with a Caregiver Advisory Committee ensured that the research was relevant, inclusive, and impactful, reflecting the real-world challenges these families face. The findings lay the groundwork for developing more effective, tailored support systems that address the unique needs of mothers in both rural and urban settings in Alberta. Several important areas warrant further investigation to build upon these findings, enhance the knowledge base, and inform support strategies for families.

Evaluating School Support for T1D

The education system's role in providing consistent support for students with T1D during school hours is paramount, not only for the immediate health outcomes of affected children but also for their long-term well-being, academic performance, and full participation in school activities. Furthermore, this support is critical for alleviating the psychological burden on families managing this chronic condition. To address these concerns, Diabetes Canada (2023) has developed a policy statement and guidelines for the care of students living with diabetes for each province and territory. However, no jurisdiction fully complies with these guidelines, and policies vary across the country. The school guidelines in Alberta, for example, are relatively recent (Alberta Education, 2019), suggesting a growing awareness of the need to support children with T1D in educational settings, yet they are not yet mandatory. There is a need for empirical research to evaluate parental satisfaction with school-based diabetes support systems and to assess the implementation, use, and efficacy of ICPs within Alberta's educational framework—and frameworks elsewhere. Such research would provide valuable insights into the real-world application of diabetes management policies in schools and identify potential areas for improvement in the support provided to students with T1D and their caregivers.

Fathers as Caregivers

Due to initiatives promoting flexible work arrangements, paternal leave, and changing aspirations of fathers desiring to be more involved in child-rearing, the amount of time fathers spend caring for their children has increased considerably since the 1970s (Sullivan-Bolyai et al., 2006). Fathers have reported feeling unprepared and anxious about illness-related care tasks and chronic disease effects on family life (Sullivan-Bolyai et al., 2006). Fathers experience psychological distress related to their child's diabetes, which may manifest differently than in mothers. As a coping mechanism, fathers often use distancing strategies when feeling overwhelmed with their child's diagnosis and care needs. This tendency may partly explain why fathers have been found to participate less in the daily care tasks or direct management of their child's chronic disease (Sullivan-Bolyai et al., 2006). For example, Chesler and Parry (2001) stated that men often find the shifting domestic roles involved in caring for an ill child stressful and challenging to undertake. In their study examining hegemonic gender expectations and fathers whose children have cancer, they found that men escaped into their employment to cope with the pressures of the complex and new responsibilities related to caring for their child with cancer. Various authors have highlighted that whereas fathers may feel distressed or burdened with their child's diagnosis, "they are reluctant to express their emotions because they perceive their most pressing role to be that of supporting their wives" (Hauenstein, 1990, p. 358). Clarke (2005) posited that the man's inability to articulate feelings and the expectation to be "a rock" for the family may constitute repression of feelings and lead to friction between spouses.

In Wiener et al.'s (2001) study on fathers caring for children with HIV, 97% of the participants expressed needing gender-specific support groups and desiring help with disease management and planning for the future. Several other studies, including Sullivan-Bolyai et al.'s (2006) study on fathers' experience with a child with T1D, have similarly found fathers to be burdened by long-term health care concerns and planning for the future. Yet despite the recognized need to consider the experiences, rewards, and impacts on fathers as caregivers, research related to paternal caregiving, especially on chronically ill children, has received little attention and instead has been focused on mothers given that they are usually primary caregivers (Swallow et al., 2012). Recognizing and addressing fathers' mental health needs is crucial for overall family well-being. Including fathers' perspectives would provide a more holistic understanding of the family dynamics and challenges in managing a child's diabetes. It could lead to developing educational programs that resonate with fathers' perspectives and learning styles, allowing for more comprehensive and effective FCC approaches.

Challenges Faced by Siblings of Children With T1D

As with the dearth of research on the impacts of caregiver burden on fathers of chronically ill children, research on the experiences of siblings of chronically sick children is also minimal. Studies including siblings as participants have generally been from a whole family perspective, failing to highlight the distinct voices of the siblings (Deavin et al., 2018). Sharpe and Rossiter (2002), in their meta-synthesis of the existing literature, concluded that siblings experienced statistically significant and overall negative effects from having a chronically ill sibling. The authors noted that siblings internalize their difficulties and suppress their anxious and depressive feelings. They attributed this behaviour to the demanding caretaking needs of the sick child and the time commitments required from parents to feed, dress, and provide treatment for that child (Sharpe & Rossiter, 2002). Dinleyici and Dağlı (2018) found comparable results in a review assessing the quality of life of healthy siblings. Findings from their study additionally suggest that healthy siblings experience lower quality of life values, symptoms of posttraumatic stress, lower peer activity, depression, anxiety, guilt, and difficulties with school.

Adding to the literature, Deavin et al. (2018) conducted a qualitative synthesis to investigate the experiences of well siblings. Results from their study identified two major themes: managing changes and managing relationships. As a result of the family's changing needs, siblings acquired new roles, responsibilities, and skills, which resulted in them developing unique ways of coping, accepting, and adjusting (Deavin et al., 2018). Siblings in their study experienced an altered sense of family cohesion. For some participants, this meant an increased sense of cohesion, whereas for others, the opposite held true. Many siblings also experienced reciprocal silence or a lack of discussion about the illness, causing them to feel isolated and unable to address their own needs. Nearly all the studies synthesized in Deavin et al.'s meta-synthesis also reported that healthy siblings experienced a shift of parental attention and experienced jealousy and resentment as a result of the time, protection, and special treatment their parents gave to the chronically ill child. Deavin and colleagues highlighted that as a coping strategy, siblings exhibited increased self-sufficiency and prosocial behaviour. In one study, for instance, healthy siblings showed tendencies to assume a pseudo-parent role and actively care for their sibling, especially if younger (Havill et al., 2019). Also noteworthy is the impact of the chronic illness on the relationship between siblings. Specifically, unwell siblings have reported being taunted by their healthy siblings and facing illness-related routines that limit their participation in shared activities (Havill et al., 2019). Although some healthy siblings have expressed a strengthened bond with their chronically ill siblings, other studies report a deterioration in the relationship (Havill et al., 2019). Findings in this regard are inconclusive and would also benefit from further investigation.

Each member of the family with a chronically ill child is impacted and experiences the burden of care in a unique way, influencing the overall family dynamic and possibly the way care is provided for a child with T1D. The above discussion sheds light on some of the experiences of fathers and siblings. It suggests that future research is required to better understand the caregiving dynamics experienced by all members of the nuclear family to develop effective support strategies for these family members. To offer more comprehensive care and FCC to families and their children with T1D, it is fundamental to understand the experiences of all members in the nuclear family unit. Integrated supports and the use of an FCC approach will necessitate ongoing evaluation and research to ensure their effectiveness.

Diversifying Participation

In addition to conducting research focused on the experiences of other family members, future studies should actively seek to include participants from diverse socioeconomic, racial, ethnic, and linguistic backgrounds; underrepresented groups such as mothers from immigrant backgrounds; and underrepresented family structures such as single parents, same-sex parents, and blended families. Including a diversity of participants would lead to more culturally appropriate interventions and support services and ensure that the potential benefits of research innovations and high-quality care are accessible to all populations. By ensuring the scope of research includes diverse perspectives, more comprehensive and equitable health care solutions can be developed that better meet the needs of all families managing childhood T1D. Although there was some diversity among the participants recruited for Studies 2 and 3, the majority of them were married, upper class, White, and had a child under 10 years of age. Few participants had children who were teenagers. Future studies primarily focused on caregivers of teenage children or of younger children could reveal important areas for targeted support. This focused representation is significant because developmental factors associated with a child's age may influence T1D management, caregiver concerns, and support needs.

Two final areas of diversification warrant further research. The first is the support needs of mothers in other parts of Canada, which may vary from those expressed by my participants from Alberta. Second, it is important to deepen the investigation into the discrepancy of care and support received in rural versus urban regions. Regionality appears to be relevant to support needs, particularly financial and access to specialized T1D care, and is an interesting factor of intersectionality to consider, as I discuss next.

Understanding Caregiver Burden Through an Intersectional Lens

When examining caregiver burden, there is a tendency to view caregiving as a one-dimensional experience (Versey, 2017). Popularized in the 1960s, the theory of intersectionality is a nonlinear way of thinking about the role of social identity categories such as ethnicity, gender, class, sexuality, geography, age, disability/ability, and migration status on health (Calasanti & Kiecolt, 2012). An intersectionality perspective aims "to understand what is experienced at the intersection of two or more axes" (Hankivsky & Christoffersen, 2008, p. 275), such as gender and class. According to Calasanti and Kiecolt (2012), through an intersectionality perspective, each of the systems of identity intersects with the others to create experiences that are nuanced. Therefore, taking an intersectional paradigm can capture the multidimensional nature of health inequities and uncover the convergence of experiences (Hankivsky & Christoffersen, 2008). Positioned to understand human differences, an intersectional approach applied to research "has the potential to create more accurate and inclusive knowledge of human lives and health needs" (Hankivsky & Christoffersen, 2008, p. 279).

Applied to the context of caregiving, addressing intersectionality of social identities allows researchers to consider a range of axes of difference to better understand the experience among caregivers. That is, intersectionality encourages a closer examination of the diverse ways in which caregivers experience their roles and workload based on the intersection of various social identities. Through this lens, policies can be developed that respond to the multiplicity of social identities and lived experiences (Calasanti & Kiecolt, 2012). Intersections create both oppression and opportunity. Whereas an intersectional position may be advantaged relative to one group, it can be disadvantaged relative to another (Shields, 2008).

Related to caregiving, for instance, a primary caregiver who is White and female may be disadvantaged because of her gender, yet she experiences racial privilege compared to a primary caregiver who is Black or of minority status (Calasanti & Kiecolt, 2012; Shields, 2008). As Shields (2008) stated, "Gender must be understood in the context of power relations embedded in social identities" (p. 302). As such, adopting an intersectional paradigm in caregiver research related to T1D fosters an understanding of the wider context of structural inequities in the experience and health of caregivers (Calasanti & Kiecolt, 2012). For example, in a Canadian study that examined the experience of caring for older adults with multiple chronic conditions, Williams et al. (2016) found gender and employment status to intersect and marginalize women more than men. They described employed female caregivers as being “squished between two places” (Williams et al., 2016, p. 9), balancing home life and work responsibilities. Participants reported this situation to cause anguish, stress, embarrassment, and sometimes tears. The pressure for some participants resulted in early retirement; for others, relocation to live closer to their elderly parent. For most participants, however, it led to a reduction in workload, which created financial challenges (Williams et al., 2016). The National Alliance for Caregiving (as cited in Versey, 2017) has estimated that the average caregiver of a chronically ill parent is a 49-year-old married woman. At this age, the majority of women are not only still in the workforce but also may have young children and families of their own (Versey, 2017). Adding elder care to the responsibilities of being an employee, mother, and wife may considerably jeopardize a woman’s well-being and health (Himes, 1994; Remennick, 2001).

Intersections can affect conditions on caregiver burden in a variety of ways. There is a limited but growing focus on understanding caregivers’ experiences, primarily based on multiple intersecting social demographics (Williams et al., 2016). Although it is difficult to determine if all possible intersections are always salient, an intersectionality lens allows for conceptualizing interlocking dynamics that affect human health and caregiving burden (Hankivsky, 2012). It embraces the complex interplay of determinants necessary to understand social inequities. That more complex understanding “can inform the development of systematically responsive and socially just health systems and policy” (Hankivsky & Christoffersen, 2008, p. 279) to address the needs of diverse groups of caregivers, including caregivers of children with T1D.

Chapter 5 References

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