

**Managing the Unmanageable through Interdependence in Adolescents Living with Type 1
Diabetes and their Parents: A Constructivist Grounded Theory**

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Abstract

Type 1 diabetes (T1D) is a chronic, incurable, autoimmune disease that generally develops before adulthood. Management of T1D requires on-going care and monitoring that demands major lifestyle changes for adolescents with T1D and their families. Maintaining, supporting, and establishing good T1D management during adolescence is important to ensure health and longevity since poor management is associated with significant long-term complications. Little is known about the nature of adolescence shared responsibility or interdependence with parents, and the characteristics of interdependence in the day-to-day management of T1D in adolescents. The purpose of this research was to describe the experiences of interdependence of adolescents with T1D and their parents. An integrative review of the qualitative and quantitative literature examining the nature of adolescent-parent interactions in T1D management showed that parental involvement was important for improved glycemic control. Limited qualitative evidence was found. Subsequently, a constructivist grounded theory approach was chosen to develop a theoretical understanding of the experiences and processes of interdependence in adolescents with T1D and their parents. Data was collected, transcribed, and analyzed from 32 open-ended online or telephone interviews of 11 adolescents aged 10–18 with T1D and eight of their parents. The substantive theory that emerged from the data describes the dynamic relationship associated with interdependence between adolescents with T1D and their parents that varies situationally and by age. Rich data related to the possibility of dying from T1D discovered in the initial grounded theory study, led to a secondary, reflexive thematic analysis. Three themes were generated: Reality of Death, Fearing the Highs and Lows, and Finding a Way through Fears that explained the participants' feelings of their fear of death. The findings fill an important knowledge gap in T1D management, providing information on how to support interdependence

in T1D management for families. The substantive theory presented in this dissertation is hypothesis generating and should stimulate future research about the role of interdependence in T1D management in other populations. Better understanding of the parent-child interaction in diabetes care will contribute important information to aid family nurses to identify and support interdependent sharing of T1D management responsibilities between parents and their adolescents.

Keywords: interdependence, adolescents, type 1 diabetes, constructivist grounded theory, parental support

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Dedication

This work is dedicated to my family:

To my husband Jeff, thank you for your love, encouragement, advice and editing skills.

To our daughter Rebecca and her husband Cody, thank you for your support, and love and constant laughter.

To our son Mikeal and his special friend Julie, thank you for the love, the hugs, and for your graphic design skills.

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...And yes, I will need each of you to call me 'doctor' at least once!

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List of Abbreviations

Continuous Glucose Monitoring (CGM)

Diabetes Family Responsibility Questionnaire (DFRQ)

Diabetic Ketoacidosis (DKA)

Hemoglobin A1C/HbA1C (A1C)

Type 1 Diabetes (T1D)

World Health Organization (WHO)

CHAPTER 1: INTRODUCTION AND OVERVIEW

1.1 Background to Research

Type 1 diabetes (T1D) is a serious chronic disease in which the pancreas produces insufficient insulin (Goldenberg & Punthakee, 2013). Currently, T1D is neither preventable nor curable, thus individuals with T1D require lifelong insulin replacement (Ekoé & Zimmet, 2011). T1D can develop at any age; however, most with T1D are diagnosed between the ages of 10 and 14 (Public Health Agency of Canada, 2011). There are approximately 30,000 school age children (5–18 years old) in Canada who have T1D (Canadian Pediatric Society, 2017).

T1D management is complex requiring an intensive regimen of blood glucose monitoring (BGM), insulin injections, diet, and exercise to achieve optimal glycemic control (Gubitosi-Klug et al., 2016). Hemoglobin A1C (A1C) is a way to monitor how well T1D is being managed as it reflects the average blood sugar for the past 60-90 days and measures the percentage of glycated hemoglobin (Punthakee et al., 2018). Lower levels of A1C are associated with lowered risk of long-term complications (Imran et al., 2013). Glycemic control for an adolescent with T1D is considered to be a fasting blood glucose in the range of 4.0-7.0 mmol/L and a glycated hemoglobin (A1C) $\leq 7.0\%$ (Wherrett et al., 2018).

Maintaining, supporting, and/or establishing optimum T1D management during adolescence is important to ensure health and longevity in this population as poor BGM is associated with significant long term complications including heart disease, stroke, nephropathy, retinopathy, and neuropathy (Gubitosi-Klug et al., 2016; Wherrett et al., 2018). Poorly controlled diabetes results in increased morbidity and mortality. Although low blood sugar can be life threatening, the main reason for keeping blood sugars in a healthy range is to prevent long term damage from high blood sugar (Rausch et al., 2012). The morbidity and mortality associated

with diabetes has significant cost to people with T1D, their families, and to the healthcare system (Diabetes Canada, 2022; Public Health Agency of Canada, 2017).

At the beginning of adolescence parents and/or guardians are major caretakers for diabetes management, and while families are likely still involved in later adolescence, the nature of the roles and responsibilities change as an adolescent with T1D takes on more of their own disease management (Foster et al., 2016). Research shows adolescence is also a period of deteriorating diabetes management and less controlled blood sugars (Hilliard et al., 2013). Potential contributing factors include nonadherence to insulin and BGM regimen, physiological changes due to puberty including increased requirement for food to fuel growth, increased insulin resistance, and preparing for transition from pediatric to adult health care (Obarcanin et al., 2015). Some familial factors that also contribute to this deterioration in T1D management are the nature of family structure and communication issues with care including conflict (Foster et al., 2016; Frey et al., 2005), critical parenting techniques (Young et al., 2014), and the amount of parental involvement (Hilliard et al., 2013). An increase in risk-taking behaviours during adolescence and having comorbid conditions including mental health challenges, can also have a negative impact on diabetes management (Raymond, 2015). Patterns of management established during early adolescence are carried into adulthood and if good management has not occurred during adolescence these patterns can be difficult to change in adulthood (Hood et al., 2009; Rausch et al., 2012).

Typically, developing autonomy in adolescence means decreasing parental involvement in the life of the adolescent; however, an adolescent with T1D is also coping with a chronic life-threatening condition which can sometimes make this increase in independence more challenging. While it is important to develop the self-management skills required for

independent living in adulthood, prematurely shifting the responsibility of diabetes management from parents to adolescents with T1D has been shown to be associated with poor diabetes management during adolescence and young adulthood (Cameron et al., 2018; Garvey et al., 2016). Some studies have shown adolescents with T1D have better self-efficacy if their parents can transfer diabetes management in a developmentally appropriate way (Wiebe et al., 2014). Adolescents with T1D have indicated they perceive it is important to take over T1D management, but they need to share T1D management with warm supportive, and caring parents while learning and gaining experience (Foster et al., 2016; Hanna et al., 2012; Strand et al., 2019). Too much and too little parental involvement can be associated with poor management of blood sugar levels (Wiebe et al., 2008). Currently studies do not precisely describe the parameters of parental involvement with diabetes management itself. However, researchers do mention that actions and attributes such as acceptance of T1D, open communication, less judgment, and proper coping with conflict by parents are associated with better T1D self-management in their adolescents (Foster et al., 2016). Research on self-care (Schilling et al., 2002), self-efficacy (Polfuss et al., 2015), and adherence (Goenthals et al., 2017) in adolescent T1D management with their parents provide insight into the potential for interdependence to be beneficial. At this time, research on the nature of interdependence in diabetes management of adolescents is limited.

Interdependence theory was first developed in social psychology as an approach to analyze social interactions (Kelley et al., 2003; Thibault & Kelley, 1959) and focussed on the properties of interactions and relationships and how those properties affect individuals within the group (Kelley et al., 2003). More specifically, interdependence theory has been applied to explain interactions within romantic relationships, business partnerships, and the division of

labour within teams (Balliet et al., 2017; Kumar et al., 2009; Wickham & Knee, 2012). In nursing the concept of interdependence has been used to describe the nature of working relationships between nurses (Huth et al, 2017). However, there is a dearth of literature applying the concept of interdependence to parent-adolescent relationships in the context of childhood chronic illness when in fact, the nature of interdependence could have application to the familial day-to-day management of T1D. Anderson et al. (1997) who explored shared responsibility in managing T1D during adolescence found that parental involvement in T1D tasks was related to better adherence and although the goal of adolescence is to develop independence an interdependent role with parents in T1D management could be relevant. However, there is currently limited description of the nature and characteristics of interdependence between adolescents and parents in the day-to-day management of T1D particularly from the perspectives of adolescents with T1D and their parents.

There is also a lack of research on how to best support parental and adolescent interdependence in T1D management, particularly from a qualitative perspective. As the number of adolescents with T1D continue to increase, more research is urgently needed to ensure optimal support, particularly throughout the challenging period of adolescence. As mentioned previously, the patterns learned at this stage of development can be difficult or even impossible to change later in life (Anderson et al., 2002; Hood et al., 2009; Rausch et al., 2012). Supporting the autonomy of adolescents who have T1D, while maintaining the potentially effective benefits of interdependence in diabetes care, merits investigation. Research of the experiences of interdependence of the adolescents with T1D and their parents could lead to better clinical support for adolescents with T1D as they take on the lifelong role of managing their complex disease.

1.2 Purpose of the Study, Specific Objectives, and Research Questions

In summary, there is a paucity of research examining and describing the role of interdependence as seen from the collective perspectives of adolescents with chronic illness and their parents. No qualitative studies were found that directly explored what interdependence means to adolescents with T1D and their parents and how effective or ineffective this approach may be. Examining the experiences and related processes of interdependence in managing T1D during adolescence could provide recommendations to improve support and outcomes for adolescents with T1D. Therefore, the overall purpose of this exploratory qualitative research study was to describe the perceived nature of interdependence with T1D management in adolescents with T1D and their parents. The specific objective of this research was to develop a substantive theory of interdependence that is grounded in the experiences and social context of adolescents with T1D and their parents.

The following research questions guided the research process:

- How do adolescents with T1D and their parents define and describe interdependence?
- What are the experiences of interdependence for adolescents diagnosed with T1D and their parents?
- What are the processes of interdependence used by adolescents with T1D and their parents?

1.2.1 Significance of the Proposed Research to Nursing

It is important for nursing professionals to have ongoing current diabetes education to ensure improvement in diabetes management in acute and community care that leads to better quality of life for people with diabetes (Kobos et al., 2020; Smith et al., 2019). This study adds to

the body of knowledge about the complex needs of adolescents with diabetes. Better understanding of the parent-child interaction in diabetes care will provide important information to aid family nurses to identify, support, and help maintain the interdependent sharing of T1D management responsibilities between parents and their adolescents. This research is hypothesis generating and as such, it can help to stimulate new nursing research to contribute to a broader base of nursing knowledge surrounding interdependence and nursing care of adolescents with T1D. As well, it could help to fill an important gap in patient care knowledge related to diabetes care and management by supporting nursing planning for patient care, educating nurses, and informing diabetes care guidelines.

1.3 Relevance of Methodological Approach in Current Study

A constructivist grounded theory approach was chosen as the methodology to address the purpose of this research and to answer the above-mentioned research questions. Grounded theory has its roots in sociology and is based on the theoretical perspective described by Mead (1964) and Blumer (1969) called “symbolic interactionism” which is a theory that focused on how people think about, give meaning to, and interpret social interactions (Blumer, 1986; Charmaz, 2014; Cutcliffe, 2000; Denzin & Lincoln, 2018). Blumer (1986) indicated that humans react to events, situations, and others according to what meaning it has for them personally and that meaning happens through social interactions. Blumer (1986) also suggested that the interpretive process is used repeatedly to modify the meaning. There are three main grounded theory approaches including Glaser and Strauss’s original grounded theory (Glaser and Strauss, 1967) Straussian grounded theory (Strauss and Corbin, 2014), and constructivist grounded theory (Charmaz, 2014). All three share common backgrounds and have some similarities, but the main differences are seen in their philosophical frameworks, their use of literature, and their coding

procedures. Grounded theory was developed in 1967 by Glaser and Strauss and as sociologists, they used positivist and postpositivist principles (Glaser & Strauss, 1967). Glaser's positivistic training in quantitative research is evident in the epistemological assumptions, logic and systematic approach of grounded theory methods, while Strauss's pragmatic philosophy, belief in symbolic interactionism, and field research are also evident (Charmaz, 2014, p. 9).

Grounded theory is iterative and comparative; the researcher makes inferences and then check them against the collected data to focus continued data collection, analysis, and theory development (Charmaz, 2014; Glaser & Strauss, 1967; Denzin & Lincoln, 2018). As data is analyzed, using constant comparison, gaps are identified, categories that fit the data are identified and concepts develop (Charmaz, 2014; Polit & Beck, 2012). This process of data collection to generate a theory is called theoretical sampling (Charmaz, 2014). Glaser and Strauss use coding when conceptualizing the data into patterns or concepts (Glaser & Strauss, 1967; Polit & Beck, 2012). Coding continues until theoretical saturation is reached. Theoretical sampling saturation is complete when no new properties of the categories are identified and a thorough understanding of the topic has been reached (Charmaz, 2014). The outcome of Glaser and Strauss' grounded theory method is the discovery of an emergent, substantive theory (Polit & Beck, 2012).

As more researchers were using grounded theory research, a division occurred in the theoretical approaches to grounded theory methodology. Glaser continued to use a mainly positivist grounded theory approach while Strauss elaborated on a more postpositivist approach (Charmaz, 2014). Strauss and Corbin in 1990 and 1998, and most recently Corbin and Strauss in 2008, presented a pragmatic evolution of the original grounded theory methodology of Glaser and Strauss (Charmaz, 2014; Creswell, 2007; Denzin & Lincoln, 2018). Strauss and Corbin indicated that the research problem could not only arise from the data as Glaser and Strauss

(1967) originally indicated but could also arise from other sources including literature or from the researchers' background and experience (Charmaz, 2014; Loiselle et al., 2011; Polit & Beck, 2012). Strauss and Corbin recognized the importance of researcher bias and took measures during data analysis to minimize this subjectivity. The outcome of the Straussian grounded theory approach is a conceptual description of the participants' experiences (Charmaz, 2014; Loiselle et al., 2011; Polit & Beck, 2012).

Charmaz was a student of Glaser and Strauss and first introduced constructivist grounded theory as an updated approach to the grounded theory methodology, which was still rooted in pragmatism and a relativist epistemology (Charmaz, 2014; Denzin and Lincoln, 2018). Constructivist grounded theory adheres to a constructivist philosophical approach (Charmaz, 2014). In constructivist grounded theory, meanings are actively constructed between researchers and participants throughout a research process which was a significant departure from the objectivist nature of the original grounded theory (Charmaz, 2014; Denzin and Lincoln, 2018). Charmaz (2014) indicated that a constructivist grounded theory approach maintains the flexibility of original grounded theory, the comparative, inductive, emergent approach of Glaser as well as Strauss' iterative logic and pragmatic emphasis on meaning and action. As constructivist grounded theory has a critical realist ontology, meanings are actively constructed between researchers and participants throughout the research process (Charmaz, 2014; Denzin & Lincoln, 2018).

Nurse researchers bring philosophical assumptions to all research they conduct, such as the nature of reality (ontology), how they know what they know (epistemology), and the methods used in the research process (methodology) (Creswell, 2007; Denzin, & Lincoln, 2018). Grounded theory is rooted in the critical realist ontological perspective (Denzin, & Lincoln,

2018; Levers, 2013). Levers (2013) describes critical realism as reality that exists “independent of the human mind regardless of whether it is comprehensible or directly experienceable” (p. 2). Constructivist grounded theory is rooted in pragmatism and is an updated approach to grounded theory as it adopted a relativist epistemology (Charmaz, 2014; Denzin & Lincoln, 2018).

Constructivist grounded theory can be used when previous research is lacking in an area of interest. It is thus seen as a fitting method for emergent research areas, as it helps to develop conceptual foundations that are grounded in data. While many studies have been conducted to investigate self-management in adolescents with T1D there is a lack of research about the concept of interdependence in these adolescents. To my knowledge, there are no qualitative studies exploring what interdependence means to adolescents with T1D and their parents. A qualitative approach to this research allows for investigation of the meanings and experiences of interdependence of adolescents with T1D from the perspective of these participants.

1.4 Fit with Proposed Research and Researcher as Instrument

Research, particularly where the researcher is part of the research process, is lacking on this topic. Through this research process, I hoped to discover a new understanding of the processes of interdependence from the perspective of parents and their adolescents with T1D. Constructivist grounded theory is well suited to this research as it allows for myself, as the researcher, to be immersed in the investigative process of the real-life experiences and the meaning the participants assign to them.

In qualitative research the researcher is considered an instrument in the study, so reflexivity and disclosure are used to increase transparency and trustworthiness of the research (Charmaz, 2014; Hall & Callery, 2001; Morrow, 2005). I have been a registered nurse in Saskatchewan for almost 30 years, and an educator for the past 18 years. My interest in diabetes

research is long standing both as a professional and as a mother with a 32-year-old son who was diagnosed with T1D at the age of five. I have met and cared for many adolescents and families impacted by T1D through my professional interests and volunteer efforts. These professional experiences, as well as my own experiences in family management of adolescent T1D, have shaped my interest and fueled a passion to investigate ways to fulfill the need for a more effective, informed, and family-centered nursing care approach.

Aside from the support of the healthcare team, my family experienced minimal support outside our own family which we found stressful. Also, the absence of systematic coaching as our son with T1D transitioned to adult care, and the lack of provincial and national funding for daily T1D management by families were troublesome. When our son was diagnosed 27 years ago, we experienced numerous challenges including financial worries, treatment stress, and the need to relocate. For example, few of the costs of T1D management were covered by our province or our health plans. As a young family just starting out, the costs of T1D management were overwhelming. We paid whatever we had to pay to keep our son healthy and that meant significant sacrifices in other areas. Since our son was a toddler, he has had a severe needle phobia, which has not improved to this day. This needle phobia has caused significant stress and alterations in his schedule in addition to the daily demands of diabetes management. Ongoing coping has been required as obviously needles are not something you can avoid when you have T1D. Our son rarely left our side even when he went to school. We moved close to his elementary school to ensure we would be only steps away should he run into any difficulties.

We tried to educate our extended family, his teachers, and coaches but, while we found a general willingness to help, there was a profound lack of understanding of T1D. My husband generally ended up coaching his extracurricular sports (e.g., flag football, soccer, basketball) all

through childhood and adolescence so that someone with knowledge of T1D was close by in case of low blood sugar during and following the activities. When our son was in high school, we sent him to the same school my husband taught at so he could be close to administer insulin or juice if our son needed. In all the years our son has had T1D there was one person, other than us, to ever take an interest or try to learn about T1D and administer our son's insulin injections. Our son had his insulin administered by a family member once, and due to the confusion and education in the moment that he had to conduct, and the resulting stress and pain he experienced, our son preferred to continue to have himself or one of us (his parents) do all of his injections. Additionally, our son was one of the first adolescents in our province to use an insulin pump. Switching to an insulin pump in his later high school years was life changing as he was able to have far more flexibility in his routine and, for example, sleep in for the first time.

Despite our son being very educated, responsible, and diligent with all of his T1D management, the ever-present worry over his wellbeing continues to this day. There was no prescribed counselling for us as parents, no support group we ever benefitted from, or extended family member that offered to share the burden. The lifestyle changes we had to make due to the cost of ensuring our son's T1D was well managed was also a constant stress for us. I have always wanted to try to somehow ensure T1D would not ever cause our son financial distress. Things have improved for T1D funding in our province and country since our son was diagnosed, but strides are still required. Someone with T1D should not have to choose between optimal management and paying for higher education, groceries, or other necessities of living.

As a nurse in hospital and nurse educator taking students to various clinical areas, I have encountered lack of understanding of T1D care in community and acute care settings. The lack of understanding of the diligent monitoring requirements for T1D is astounding to me and instills

additional worry for what happens to people with T1D when they require medical care. I have always thought there must be a better way for people and families living with T1D, and subsequently hoped that researching others' experiences could be a way to start to make some positive changes. Thus, my background, professional and personal experiences, and the choice of the constructivist grounded theory methodology allowed for a unique examination and consideration of the social processes involved in interdependence from the perspective of the participants in this study.

1.5 Organization of the Dissertation

This dissertation is presented in a manuscript-style format and describes the progression of my research. This chapter provides an introduction to the research that includes the background, purpose, objectives, research questions, and discussion of the constructivist grounded theory approach. This chapter ends with a reflection of what I bring to this research. Chapter Two is comprised of an integrative review (Farthing et al., 2022) and includes presentation of the assessment of the extent and nature of published research regarding the interdependent parent-adolescent relationship in T1D management. In Chapter Three, the major findings of this constructivist grounded theory research are discussed (Farthing et al., in press). Chapter Four is a presentation of the findings from a reflexive thematic analysis that arose from the discourse with parents and adolescents. The analysis explores the perceptions of fears related to death in adolescents and their parents associated with the diagnosis and management of T1D. The manuscripts in Chapter Two and Three were recently accepted for publication in peer reviewed nursing journals. Both Chapter Two and Chapter Three have been formatted from their published versions for inclusion in this dissertation. Chapter Four will be revised for submission to a peer-reviewed journal for publication. Finally, Chapter Five presents a comprehensive

discussion of the contributions to the existing literature of each manuscript contained within this dissertation. Additionally, the strengths and limitations of this research, overall conclusions, implications, and future areas of research are discussed in Chapter Five.

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CHAPTER 2: TYPE 1 DIABETES MANAGEMENT RESPONSIBILITIES BETWEEN ADOLESCENTS WITH T1D AND THEIR PARENTS: AN INTEGRATIVE REVIEW

2.1 Relationship of Manuscript One to the Dissertation

The following manuscript includes a synthesis of the qualitative and quantitative evidence regarding the parent-adolescent relationship in blood glucose management of adolescent T1D. Of particular interest was the role of interdependence in this relationship. This manuscript aligns with and supports the dissertation by presenting a synthesis of the research literature related to parent-adolescent dyadic relationships concerning interdependent aspects in blood glucose management of adolescent T1D. It provides a basic understanding of the state of current research around the topic of interdependence in adolescent T1D care. The review helped to identify gaps in research knowledge that supported development of the research questions for this dissertation and assisted in generating new perspectives by helping to define interdependence and related concepts.

2.2 Manuscript One

Farthing, P., Bally, J., Rennie, D. C., Dietrich Leurer, M., Holtslander, L., & Nour M. A. (2022).

Type 1 diabetes management responsibilities between adolescents with T1D and their parents: An Integrative Review. *Journal for Specialists in Pediatric Nursing*, 27(4),

Article e12395. <https://doi.org/10.1111/jspn.12395>

Permission was granted by the publisher to include this manuscript in the dissertation.

This manuscript was completed in collaboration with, Dr. Bally and Dr. Rennie, my co-supervisors in this dissertation, as well as my committee members, Dr. Dietrich Leurer, Dr. Holtslander, and Dr. Nour. My contributions included: conceptualization, conducting the data collection and analysis, writing the initial draft, incorporating feedback from Dr. Bally and Dr.

Rennie on subsequent drafts, and preparing the manuscript to meet journal guidelines for submission. Drs. Bally and Rennie's contributions included assistance with conceptualization, reviewing, editing, providing critical feedback, and supervision. Drs. Dietrich Leurer, Holtslander, and Nour provided expertise, final draft editing, and feedback.

2.3 Abstract

Diabetes self-management for adolescents with type 1 diabetes (T1D) is a complex and multifaceted process that requires careful consideration of a supportive or shared approach to care. The purpose of this review was to synthesize the qualitative and quantitative evidence regarding the nature of adolescent-parent interactions and relationships in the context of T1D management. Of particular interest was the role of interdependence in this relationship.

An integrative review of the literature was conducted between January 2021 and April 2021 using Whittmore and Knaf's (2005) methodological strategies. Eleven studies published between 2003 and 2018 met the review criteria. Thematic analysis identified the following three themes related to parent-adolescent relationships in care including the Effectiveness of Parental Involvement and T1D Management, Shared Responsibility and T1D Task Management, and Gaining Independence in T1D Management. This review highlights the importance of both parent and adolescent shared involvement in T1D management. In particular, parental involvement appears necessary for improved glycemic control, better adherence to the T1D management regime, and for practicing self-management in adolescents with T1D.

Keywords: type 1 diabetes, interdependence, adolescent(s), parent(s), shared responsibility

2.4 Type 1 Diabetes Management Responsibilities between Adolescents with T1D and their Parents: An Integrative Review

There are many facets to the day-to-day management of those with type 1 diabetes (T1D) including blood glucose monitoring, dietary management, insulin administration, and lifestyle modification (Punthakee et al., 2018). For children with T1D, parents or caregivers are often the family member helping or overseeing management of diabetes care to ensure optimal glucose levels. However, parental roles and responsibilities will change as adolescents with diabetes take on more of their own disease management (Foster et al., 2016). Maintaining, supporting and/or establishing optimal T1D management during adolescence is important to ensure health and longevity in this population as poor blood glucose management is associated with significant long-term complications (Wherrett et al., 2018).

Adolescence is a stage of developing autonomy which typically means less parental involvement, but an adolescent with T1D is also coping with a serious life-threatening illness. Increasing responsibility for self-care creates additional complex challenges to the management and treatment of diabetes during this time. While independence and self-care are the primary objectives of T1D management for adolescents (Polfuss et al., 2015; Wherrett et al., 2018), research also points to a sharing of diabetes management or interdependence between adolescents and parents (Anderson et al., 1997; Trudeau et al., 2019) as a better solution to managing diabetes.

Interdependence theory was first developed in social psychology as an approach to analyze social interactions (Kelley et al., 2003; Thibault & Kelley, 1959). Theories in human psychology mainly focus on individuals, whereas interdependence theory focusses on the properties of interactions and relationships between people or groups and how those properties

affect individuals (Kelley et al., 2003). Interdependence theory has been applied to understand interactions within romantic relationships, business partnerships, and the division of labour within teams (Balliet et al., 2017; Kumar et al., 2009; Wickham & Knee, 2012). However, there is a dearth of literature applying the concept of interdependence and interdependence theory to parent-adolescent relationships in the context of childhood chronic illness. Anderson et al. (1997) mentioned interdependence and advocated that parents play an important role in managing T1D in adolescence through sharing, collaboration, and partnerships but, little is known about the parent-adolescent interaction in T1D management and interdependence. Views of these roles may differ between parent and adolescents and, therefore, there is a need to assess the extent and nature of research from the perspectives of both the parent and the adolescent with T1D. The initial search of research literature examining interdependence in diabetes care of adolescents led to the recovery of no relevant articles, so the research question was broadened to capture all potential research related to interdependence and associated key words as they applied to the management of adolescent T1D by families. The research question guiding this review was: What is the state of the qualitative and quantitative research literature regarding parent-adolescent relationships including interdependence in blood glucose management of adolescent T1D?

2.4.1 Methods

To ensure a rigorous review of the literature, Whitemore and Knafl's (2005) methodological approach for integrative literature reviews was used including the following five stages which were used to guide the review: problem identification, literature search, data evaluation, data analysis, and data presentation. An integrative literature review was chosen to ensure a more holistic understanding of both the qualitative and quantitative literature related to

the concept of parent-adolescent relationships that could inform future research and nursing practice (Whittemore & Knafl, 2005).

2.4.1.1 Problem Identification

Interdependence is how people benefit when they rely mutually on each other for survival or success; yet, as stated above, the current practice in the care of children and adolescents with T1D is encouragement towards independence and self-reliance in disease management (Huth et al., 2017; Wherrett et al., 2018). The concept of interdependence, while more widely used in management of professional groups (Huth et al., 2017), is suggested by some to be important in family management of T1D in adolescents (Anderson, 1997; Trudeau, 2019). However, to date, little synthesis of the related literature is available. Therefore, the purpose of this review was to synthesize the qualitative and quantitative evidence regarding the nature of adolescent-parent interactions and relationships in the context of T1D management. Of particular interest was the role of interdependence.

2.4.1.2 Literature Search

Four databases were searched with the aid of an academic librarian and included articles up to February 15, 2021. Databases included Medline®, CINAHL®, PubMed®, and PsycInfo™. The following main MeSH headings were used to retrieve the most relevant articles. Four separate searches were completed in the following order: 1) *Diabetes Mellitus OR Type 1 diabetes mellitus*; 2) *Adolescent OR adolescen* OR teen**; 3) *Parent**; 4) *Interdependence OR shared responsibility OR self-care OR support OR self manag* OR social support OR psychological adaptation OR psychological support OR parent-child relations OR parental support*. The four main MeSH headings were then combined with the additional Boolean

operator *AND* for a more targeted search. Ancestry searching of reference lists was also used to find articles. Dissertations and grey literature were not included.

The initial search of the literature included titles and abstracts of peer-reviewed articles from any country published in the English language; only those articles that included ages 10-18 years; no limits on the date of publication; and only research-related qualitative, quantitative, or mixed methods studies were included. As the focus of the review was adolescents, a lower limit of 10 years was used as it complied with the lower age limit of adolescence as defined by the World Health Organization (WHO) (2022). The literature search returned 5450 records and 2556 articles remained after duplicates were removed.

To ensure that the most relevant articles were chosen, the next step in the search was conducted by two reviewers (PF and DR) using the following criteria: Included studies had to: (1) contain the perspectives of both parents and adolescents; (2) represent participants who were at least one year since a diagnosis of T1D; (3) be from westernized countries to ensure similar T1D management guidelines (Cameron et al., 2018). In studies where children of other ages were included, we reported information that specifically pertained to those who were in the 10- to 18-year-old age group.

Studies were excluded: (1) where the main focus was not T1D or where the main focus was on intervention, adherence, or compliance with prescribed care; (2) if they involved instrument development, or psychometric testing related to assessing parent-child relationships or executive functioning; (3) intervention or innovation studies involving clinical management of T1D; (4) where the main focus was on assessment of parent-child relationship outcomes regarding mental health issues or family dysfunction.

The abstracts were screened by title for inclusion and exclusion independently by the reviewers (PF and DR). The reviewers met to re-review those abstracts where independent decisions were in disagreement. During this process 158 abstracts were re-examined, and an additional 111 abstracts were excluded. The remaining 47 abstracts were reviewed in full by a third reviewer (JB). All three reviewers then met to discuss the final 47 articles with an additional 37 articles excluded by consensus of the review panel (PF, JB, and DR). Ancestry searching resulted in one additional article being included for a total of 11 relevant research articles being included in this integrative review (See Figure 2.1).

2.4.1.3 Data Evaluation

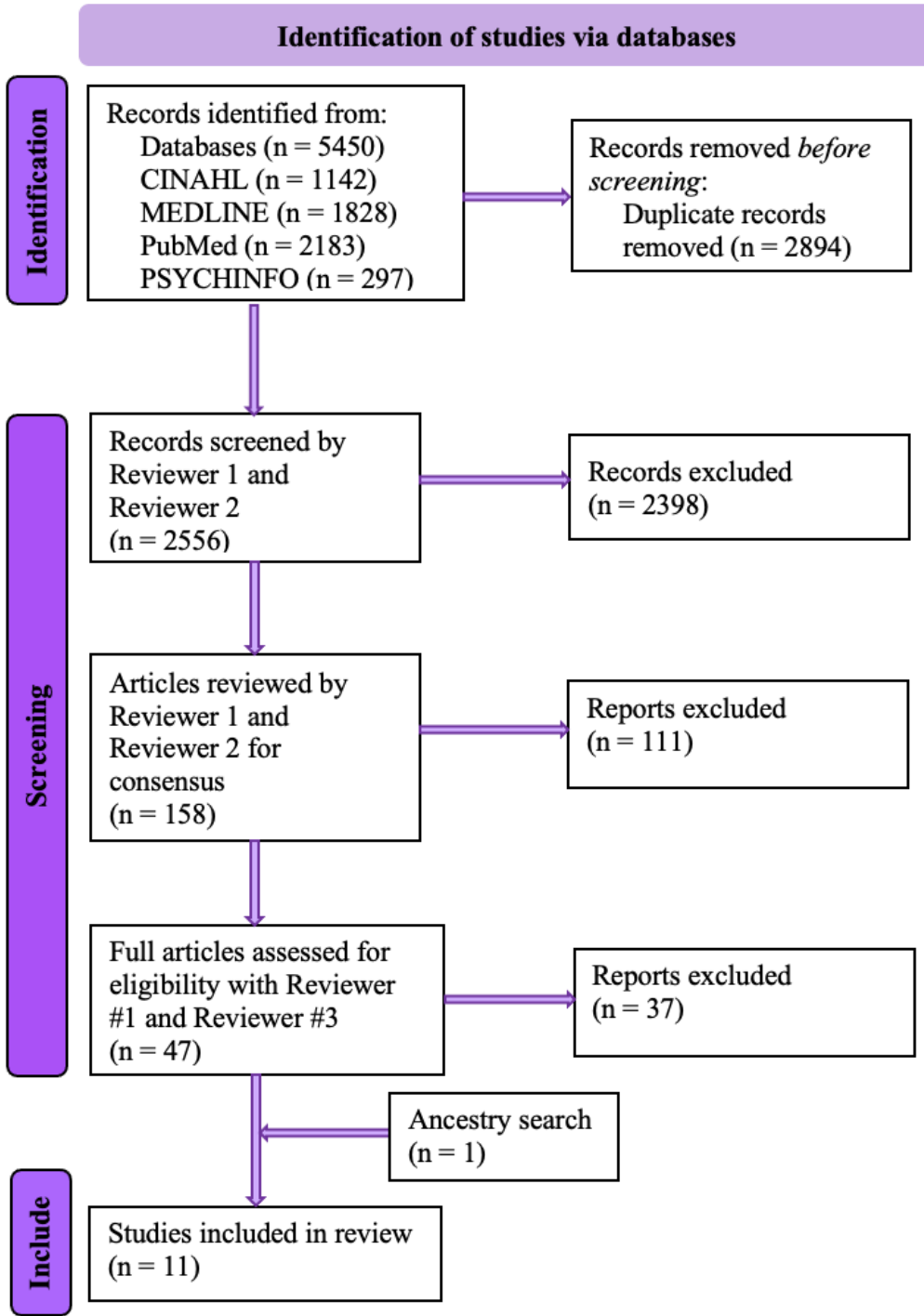
The articles were evaluated using the McMaster University protocols for critical review of qualitative (Letts et al., 2007) and quantitative (Law et al., 1998) research articles. Qualitative studies articles were also scrutinized using a standardized appraisal checklist (Critical Appraisal Skills Program [CASP], 2017) and a quality scoring method by Duggleby et al. (2010). CASP consists of 10 questions: two for screening out inapplicable studies and eight remaining questions that assessed the appropriateness of research methods and rigour (CASP, 2017). Duggleby et al. (2010) developed an additional three-point rating system (1–3) as to how well the topic explained the methodology, with a higher score indicating better explanation. No studies were excluded because of CASP appraisal or scoring.

2.4.1.4 Data Analysis

Whittemore and Knafl's (2005) updated integrative review methodology consisting of a four-phase constant comparative method was used to examine articles. Articles were read several times by the first author and findings from all articles were compared through an iterative process until analysis was complete and an innovative synthesis was captured. Data were

Figure 2.1

Literature Review PRISMA Flow Diagram



Page et al. (2021)

extracted using the following headings as a template for qualitative articles: author/country; study objective; study population; design; method/data collection; and key findings. Similarly for quantitative studies, the following headings were used as a template for data extraction: author/country; study objective; study population; design; method/data collection (measures of responsibility, measures of metabolic control); and key findings. The data was reduced, categorized, and coded to facilitate analysis of the studies for similarities, differences, and patterns (Whittemore & Knafl, 2005). In addition, the data were divided into qualitative and quantitative study methodologies and were examined separately. Studies were conceptually classified according to the purpose and other characteristics of each study (e.g., age, the parent participating, duration of T1D). Next, key findings of each study were examined for strengths and weaknesses and compared for cross-cutting themes. Results from all articles were then examined collectively in a final synthesis of themes to answer the research question.

2.4.1.5 Data Presentation

The findings are presented in table format (see Tables 2.1 and 2.2). The 11 articles selected for the integrative review were published between 2003 and 2018. All were conducted in the United States. A variety of different research approaches were taken to study parent-adolescent relationships and interdependence. No randomized control trials were identified. The most common quantitative design was cross-sectional in nature (Anderson et al., 2009; Dashiff et al., 2003; Geffken et al., 2008; Hanna et al., 2012; Marker et al., 2018; Vesco et al., 2010), followed by three short prospective studies (Helgeson et al., 2008; Hilliard et al., 2013; Ingerski et al., 2010). The qualitative studies (n = 2) included in this review were a content analysis of a selected 10-minute excerpt interaction between parent and child (Ivey et al., 2009) and a qualitative descriptive design of interview transcripts (Schilling et al., 2006).

Table 2.1

Summary of Qualitative Studies Evaluating Parental/Adolescent Responsibility for Adolescent T1D Management Tasks

Author and Country	Objective	Study Population	Design	Methods/ Data Collection	Key Findings	CASP SCORE
Ivey et al. (2009) USA	To describe the ways adolescents and parents communicate during management of T1D	Adolescents (age 11-15) with T1D and A1C ↑11 or ↓7 and their parents N=28 triads	Secondary content analysis of early-stage data taken from a larger longitudinal study	-Analysis completed on preselected 10min audiotaped interactions (taped during the 2 hours data collection visit of the larger study) where there was an issue of disagreement between adolescents with T1D and their parents about a management task. -The adolescents chose the event to be analyzed	-Five themes identified including frustration, fear, normalizing, trusting, and discounting -Trusting the adolescent to manage diabetes was difficult for the parents and was associated with frustration, fear, and discounting communication	17
Schilling et al. (2006) USA	To describe tasks of self-management in youth with T1D	Youth (age 8-19) with T1D and at least one parent N=22 dyads	Qualitative Description	Semi-structured audiotaped interviews	-Three themes of T1D management emerged (a) Division of labor (b) Nature of conflict (c) Degree of transfer of responsibility -Responsibility for T1D tasks being completed shifting to child according to their developmental stage -Three stages identified including, Parent dominated, transitional, and adolescent dominant -As youth get older, they take on more self-management responsibility -More variability in self-management at mid-adolescence than in other stages -Most conflict was associated with diet and BGM	20

Table 2.2

Summary of Quantitative Studies Evaluating Parental/Adolescent Responsibility for Adolescent T1D Management Tasks

Author and Country	Objective	Study Population	Design	Methods/Data Collection		Key Findings
				Measures of Responsibility	Measures of Metabolic Control	
Anderson et al. (2009) USA	Assess relationship between glycemic control and dyadic agreement and discordance for responsibility	Children with T1D (age 9-14) and a parent or caregiver N = 121 dyads	x-sectional	-DFRQ ¹ 17 item diabetes responsibility management scale -DFCS ² conflict scale	Glycemic control= A1C measured within two weeks of baseline assessment	- Parental report of ↑dyadic agreement was associated with ↓A1C (p<.05) - Discordance in sharing responsibility was inversely correlated with age (p<.01)
Dashiff et al. (2003) USA	Assess congruence of diabetes care and adolescent and parental responsibility	Adolescent with T1D (age 12-15) and both parents N = 31 dyads	x-sectional	-DFRQ reduced to 15 items Self-administered.	A1C twice, two months apart	-No association between adolescents' and fathers' perceptions of mothers' responsibilities (p = 0.53) -DFRQ not associated with A1C
Geffken et al. (2008) USA	Assess diabetic ketoacidosis (DKA) and parental attitudes/responsibility for diabetes tasks	Children with T1D (age 7-18) and a parent N = 100 dyads	x-sectional	-DFBS ³ 23-item warmth subscale (child) -DFBC ⁴ 7 item subscale (parental negativity) -DFRQ no responsibility score added to scale	DKA determined by chart review	-Youth reports of ↑parental warmth and ↓parental negativity of diabetes management regimen ↓risk for DKA episode (p<.05) -Responsibility score not associated with DKA episodes
Hanna et al. (2012) USA	Assess if parental autonomy support for adolescents is associated with shared diabetes care responsibility	Adolescents with T1D (age 12-17) and a parent N = 87 dyads	x-sectional	Parental Support for Adolescent's Autonomy Development Scale ⁵	Responsibility Subscale ⁶ 15 items (unpublished)	-↑parental autonomy support associated with ↑ shared responsibility (parents, p<.01); adolescents, p<.01) - ↑ adolescent age ↓parental autonomy support (adolescent, p<.001) and ↓ shared responsibility (parent, p<.01)
Helgeson et al. (2008) USA	Assess importance of responsibility for adolescent psychological behaviors and diabetes outcomes	Adolescents with T1D (age 10-14) and a parent N = 132 dyads	2-year Prospective Cohort (Baseline, T1, T2)	-DFRQ no responsibility score added to scale -CDI ⁷ 10 item assessed depressive symptoms -CMAS ⁸ 7 item modified anxiety scale	-MDQ ¹¹ self-efficacy 7 item subscale -SCI ¹² to measure diabetes self-care -A1C collected at each clinic visit	-Adolescent: ↑shared responsibility associated with ↓depressive symptoms and ↓anger (p<.05); ↑Parent responsibility associated with ↓social competence (p<.05), and ↑anger (p<.01)

				-DES ⁹ 3 item anger subscale -SPPC ¹⁰ two subscales: social competence		-Shared responsibility predicted ↑diabetes self-efficacy (p<.05) ↑self-worth, and ↓A1C (p<.05)
Hilliard et al. (2013) USA	Assess paternal involvement in diabetes management	Children with T1D (age 9-12) and both parents N = 146 triads	3-year Prospective Cohort (Baseline, T1, T2, T3)	-DADS ¹³ 24 item scale for paternal diabetes management -DSMP ¹⁴ 25 items of diabetes self-management	-Adherence by BGM: Average daily BG for 2 weeks -A1C collected at each study visit	-Fathers' involvement ↓over time. -Lower levels of fathers' perceived contribution predicted ↑youths' self-management (p<.05) -DADS scores for both parents did not predict BGM frequency or A1C
Ingerski et al. (2010) USA	Assess family responsibility and family conflict, time and age trends for diabetes monitoring and control	Adolescents with T1D (age 13-18) and a parent N = 137 dyads	6-month Prospective Cohort (Baseline, T1)	-DFRQ 17 item -DFCS -CDI 27 item depression scale	BGM self-report adjusted frequency A1C	-↑adolescent age responsibility shifts from parent to adolescent (p<.01) -↑ family responsibility scores associated with ↑BGM frequency for both adolescent (p<.01) and parent reports (p<.05)
Marker et al. (2018) USA	Assess relationship between shared responsibility and glycemic outcomes	Adolescent with T1D (age 10-16) and a parent N = 35 dyads	x-sectional	DFRQ Percent responsibility attributed to the youth, parent, or both (shared)	-Glycemic control: A1C -Adherence: Self-monitoring blood glucose (SMBG) -Glucose variability: 3 BG measures/day for 14 days	- Shared responsibility associated with ↓glycemic variability (parent report) and ↓risk of glycemic excursions (adolescent report) (p<.001). No association with A1C -Parent responsibility associated with ↑ glycemic variability (p<.001) and ↑risk of glycemic excursions (p<.05)
Vesco et al. (2010) USA	Assess associations of shared responsibility for direct and indirect diabetes tasks	Adolescents with T1D (age 13-18) and a parent N = 261 dyads	x-sectional	DFRQ Subdivided into direct and indirect tasks Interviewer administered	A1C BGM daily frequency or self-report adjusted frequency for 14 days	-Adolescent report of ↑ caretaker responsibility (direct tasks) associated with ↑ BGM frequency for DFRQ (p<.05) -No associations between DFRQ and A1C

¹Diabetes Family Responsibility Questionnaire (DFRQ) (Anderson et al., 1990). ²Diabetes Family Conflict Scale (DFCS) (Hood et al., 2004). ³Diabetes Family Behaviour Scale (DFBS) (Waller et al., 1986). ⁴Diabetes Family Behavior Checklist (DFBC) (Schafer et al., 1983). ⁵Parental Support for Adolescent's Autonomy Development Scale (Hanna et al., 2005). ⁶Responsibility Subscale (Peyrot, unpublished). ⁷Children's Depression Inventory (CDI) (Kovacs, 1985) ⁸Revised Children's Manifest Anxiety Scale (CMAS) (Stark & Laurent, 2001). ⁹Differential Emotions Scale (Izard et al., 1993). ¹⁰Self Perception Profile for Children (SPPC) (Harter, 1985). ¹¹Multidimensional Diabetes Questionnaire (MDQ) (Talbot et al., 1997). ¹²Self-Care Inventory (SCI) (La Greca et al., 1988). ¹³Dads' Active Disease Support Scale (DADS) (Wysocki & Gavin, 2004). ¹⁴Diabetes Self-Management Profile (DSMP) (Harris et al., 2000).

The Diabetes Family Responsibility Questionnaire (DFRQ) developed by Anderson et al. (1990) and modified by others (Dashiff et al., 2003; Helgeson et al., 2008; Vesco et al., 2010) was the scale most often used to evaluate parental involvement in care. The DFRQ rates different tasks (e.g., rotating injection sites) or situations (e.g., noticing early signs of an insulin reaction). The DFRQ scale used is “1 = parent(s) take or initiate responsibility for this almost all the time, 2 = parent(s) and child share responsibility for this about equally or 3 = child takes or initiates responsibility for this almost all of the time” (Anderson et al., 1990, p. 492). Interrater reliability of this tool was available for five studies and was relatively good ranging from 0.67 to 0.85 for the parent tool and 0.71 to 0.84 for the adolescent tool.

The outcome variables for the quantitative studies varied but A1C followed by daily blood glucose were the most common outcomes evaluating parental involvement and diabetes well-being in the adolescent. The DFRQ was infrequently associated with better A1C (Dashiff et al., 2003; Ingerski et al., 2010; Marker et al., 2018; Vesco et al., 2010). As required, eight studies included dyadic information from both parents and adolescents while three studies included data from both parents and the adolescent (triads) (Dashiff et al., 2003; Hilliard et al., 2013; Ivey et al., 2009).

The mother was the most frequent caregiver participant in all studies of dyads in the review. Through the search, the authors did not find articles that examined interdependence in detail. The following is a presentation of the findings from this review including three main themes: Effectiveness of Parental Involvement and T1D Management, Shared Responsibility and T1D Task Management, and Gaining Independence in T1D Management.

2.4.1.5.1 Effectiveness of Parental Involvement and T1D Management. Effectiveness of Parental Involvement and T1D Management encompassed any interactions of parents with

their adolescents that related to the management of T1D and included communication, parenting style, and level of involvement. Eight studies elucidate the effects of parental involvement in the management of T1D in adolescents (Anderson et al., 2009; Geffken et al., 2008; Helgeson et al., 2008; Hilliard et al., 2013; Ingerski et al., 2010; Ivey et al., 2009; Marker et al., 2018; Vesco et al., 2010). Parental involvement in diabetes related tasks was assessed using a variety of measures and the results from each study were examined for the overall effectiveness, amount, type, and impact of parental involvement.

Parental support was shown to be effective for day-to-day diabetes management. In a cross-sectional study of parent/adolescent (age 13–18) dyads, Vesco et al. (2010) found that adolescents with T1D were more likely to check their blood sugar regularly if their parents were involved. This finding is supported by a 6-month prospective cohort study of 137 parent/adolescent dyads (age 13–18) conducted by Ingerski et al. (2010) where parent involvement throughout the study predicted regular blood sugar assessment by their adolescent. Anderson et al. (2009) conducted a cross-sectional study with 121 dyads of youth with T1D (age 10–15). Parental involvement in diabetes management tasks reported by both parents and adolescents was found to be significantly associated with lower A1C in adolescents with T1D ($p < .01$) (Anderson et al., 2009).

There were limited studies examining the extent of parental involvement. However, the amount of parental involvement may be an issue with management outcomes. Marker et al. (2018) studied 35 dyads ages 10–16 years and found that parent reports of more parental responsibility for diabetes management tasks was significantly associated with increased glycemic variability ($p < .001$) and an increased risk of glycemic excursions ($p < .05$).

In a three-year prospective study of 146 triads of both parents and their child aged 9–12 with T1D, Hilliard et al. (2013) found the most frequent parental report was by the mother. They also found mother's and child's perceptions of parental involvement were in agreement, however, fathers tended to be poorer judges of others' involvement.

Parental involvement also impacts psychosocial and emotional outcomes in adolescents with T1D (Geffken et al., 2008; Helgeson et al., 2008; Ivey et al., 2009). Helgeson et al. (2008) conducted a prospective cohort study of 132 dyads of a parent and adolescent (age 10–14) and found that adolescents' report of greater parental involvement in diabetes management tasks was significantly associated with lower social competence ($p < .05$) and increased anger ($p < .01$). Geffken et al.'s (2008) cross-sectional study of 100 dyads of a parent and their child (age 7–18) with T1D found significantly less risk for diabetic ketoacidosis (DKA) episodes when adolescents with T1D reported more parental warmth and less parental negativity of diabetes management regimen ($p < .05$). In a qualitative study of 28 parent and adolescent (age 11–15) triads, Ivey et al. (2009) found that if parents had difficulty trusting adolescents to manage their T1D, there was frustration, fear, and parents discounting communication by the adolescent (Ivey et al., 2009).

Overall, parental involvement in diabetes management tasks for their adolescent is more likely to improve glycemic control and results in less relational conflict (Anderson et al., 2009; Geffken et al., 2008; Ingerski et al., 2010; Vesco et al., 2010). However, the level and variety of parental involvement and how it occurs appears important for glycemic control and the psychosocial health of the adolescent (Helgeson et al., 2008; Hilliard et al., 2013; Ivey et al., 2009; Marker et al., 2018) and requires additional investigation.

2.4.1.5.2 Shared Responsibility and T1D Task Management. Shared Responsibility and T1D management included assessment of the division of T1D tasks between parents and their adolescents at a particular point in time or as their adolescent aged. These T1D tasks were directed at achieving self-management and improvement in glycemic control. Five studies discussed the importance of shared responsibility, referring to both parent and adolescent being involved with T1D management (Anderson et al., 2009; Dashiff et al., 2003; Hanna et al., 2012; Helgeson et al., 2008; Marker et al., 2018). Studies either identified shared responsibility and its influence on glycemic control (either a fasting blood glucose of 4.0–7.0 mmol/L and/or a glycosylated hemoglobin [A1C] \leq 7.0% [Wherrett et al., 2018]), and/or examined shared responsibility in the context of overall wellness of the adolescent with T1D. The majority of these studies used the DFRQ to evaluate shared responsibility.

Anderson et al. (2009) found shared diabetes management leads to improved glycemic control. Specifically, clear communication between parent and adolescent about task responsibility helped to reduce conflict (Anderson et al., 2009). As well, older adolescents in the study had significantly lower conflict with their parents about sharing T1D management tasks ($p < .01$). Helgeson et al. (2008) found that parents and adolescents with T1D reports of shared responsibility were associated with adolescent reports of increased diabetes self-efficacy. In addition, adolescents' reports of shared responsibility significantly predicted increased self-worth ($p < .05$), significantly increased self-efficacy or self-management ($p < .05$), and lower A1C ($p < .05$). The authors also found that adolescents with T1D reported significantly fewer depressive symptoms ($p < .05$) and decreased anger ($p < .05$) when experiencing shared responsibility with a parent. Marker et al. (2018) found that shared responsibility decreases both glycemic variability and excursions.

Despite the improvements to glycemic control and overall wellness, some studies indicated that shared responsibility waned with increasing age of the adolescent or was ill-perceived by the adolescent with T1D and their parents (Dashiff et al., 2003; Hanna et al., 2012). In a cross-sectional study of 87 parents and adolescents with T1D (age 12–17) Hanna et al. (2012) tested the relationship between parental autonomy support and shared responsibility in a model of interdependence. They found that as parental autonomy support increased, shared responsibility for both parents ($p < .01$) and adolescents ($p < .01$) also significantly increased. Dashiff et al. (2003) studied 31 triads of adolescents (age 12–15) and both parents and found that while the responsibility of mothers and adolescents were significantly correlated ($p = .03$), fathers' perceptions of the mother's responsibility were weaker ($p = 0.53$), indicating these differences could lead to disagreement about management strategies within the triad.

Shared responsibility has been shown to improve glycemic control (Anderson et al., 2009; Helgeson et al., 2008; Marker et al., 2018). The mother's involvement with older adolescents may be under reported in studies (Dashiff et al., 2003; Hanna et al., 2012). Future investigation of informal involvement of parents in sharing responsibility particularly during older adolescence is needed. To date research reviewed does not indicate how to best share responsibility at what ages, nor how to optimally communicate within the dyad/triad.

2.4.1.5.3 Gaining Independence in T1D Management. The ultimate goal of T1D management during adolescence is the ability for the adolescent to be able to Gain Independence in T1D Management and, therefore, direct their own care as an adult. Several of the articles indicated the importance of parents facilitating the development of diabetes self-management skills in their children during adolescence. Self-management refers to all the tasks that must be performed to achieve optimal glucose control and avoid long-term complications of T1D

(Sherifali et al., 2018). Parents are often responsible for all or most of the care of their young child with T1D, but adolescents generally begin to take on more or all of the responsibility for their diabetes care as they mature (Lewandowski & Drotar, 2007). There are many factors that influence the development of self-management in adolescents with T1D including time since T1D diagnosis, and the age and maturity of the adolescent with T1D. Studies in this review reported factors that influenced the developing self-management and self-efficacy in adolescents with T1D (Hanna et al., 2012; Hilliard et al., 2013; Ivey et al., 2009; Schilling et al., 2006).

Hilliard et al. (2013) found that parental involvement in diabetes management tasks significantly decreases over time for both parents ($p < .01$). In a cross-sectional study of 87 dyads, Hanna et al. (2012) found that parents reported significantly decreasing shared responsibility with increasing age of the adolescent ($p < .01$). However, in the same study adolescents reported that parental autonomy support significantly decreases with increasing age ($p < .001$).

Schilling et al.'s (2006) study of 22 dyads of parent and youth (8–19 years) with T1D found that parents varied their responsibility as the child aged with more involvement in early adolescence although even for later adolescents, who managed much more of their care, parents were still relied upon for some care management. Also, Schilling et al. (2006) introduced the notion of 'pinch hitting' in early and mid-adolescence (11–16 years), where the parent takes over one or more of the T1D management tasks to give the early adolescent a break from the responsibility of T1D self-management. Ivey et al. (2009) found parents have a fear of long-term complications of T1D as their adolescent ages. This fear, manifested in a lack of trust for the adolescent self-management, led to exhibited discounting communication that inhibited young adolescents' expression of feelings and ideas about diabetes management; thus, ultimately undermining adolescent autonomy and self-management (Ivey et al., 2009). This discounting

behaviour was viewed as particularly detrimental to adolescents' development of T1D self-management.

Although adolescents with T1D should progress towards self-management as they age to adulthood, parents seem to still play a role in encouraging or inhibiting this progress. Future research is needed to determine when to begin encouragement towards self-management, how exactly to facilitate self-management effectively, and who should be involved in the facilitation.

2.4.2 Discussion

The articles in this review demonstrate that parent-adolescent relationships are key for the adolescent with T1D to gain self-management skills and maintain glycemic control. However, it is a balance of parental involvement, as too much or too little involvement was shown to be associated with suboptimal blood glucose management. The parameters or nature of the parent-adolescent relationship with diabetes management itself are not described in the review. However, actions and attributes such as acceptance of the disease, open communication, less judgment, and proper coping with conflict by parents are associated with better diabetes self-management in their children (Dashiff et al., 2003; Geffken et al., 2008; Ivey et al., 2009). Our review also found it was important to consider the developmental level at the time of the interactions (Schilling et al., 2006). In an overview examining barriers to adherence and potential interventions, Borus and Laffel (2010) indicated that developmentally appropriate parental involvement was seen as an important factor for optimal T1D management in teens. As well, in an investigation of parental responsibility and adolescent self-efficacy and maturation, Wiebe et al. (2014) found that transfer of responsibility from parents to adolescents was optimal if it is titrated to their child's maturity level.

Many studies in this review used the DFRQ tool to measure sharing of responsibilities for T1D. However, it was often modified between studies, making findings of these studies difficult to compare. As well, items on the DFRQ do not reflect current important tasks in T1D management (e.g., supplies used, calibration of equipment and lifestyle modifications for insulin pumps or continuous glucose/flash glucose monitors). With regard to interdependence, the DFRQ addresses tasks and roles between parent and children and assesses agreement and disagreement between responsibility for these roles rather than examining the quality of the relationships or the nature of interdependence directly.

Although the articles in this review do not describe when effects of parental involvement, shared responsibility, and self-management are best manifested, it is evident that age seems to be a factor for all three themes. Specifically, the findings presented in the articles indicate that the responsibilities of parents and their adolescents for diabetes management tasks changes as the adolescent ages. Trudeau et al. (2019) agrees with Schilling et al. (2006) by indicating that as the adolescent with T1D ages the involvement of the parent moves from parent-dominant care to shared responsibility to adolescent dominant self-management. Trudeau et al. (2019) suggest that adolescent self-management is not the end of a journey and that a final stage is one of interdependence where the older adolescent with T1D, the parents, and diabetes healthcare team all work together to support T1D management.

Interestingly, one of the search terms for this review was interdependence yet the literature in this review rarely mentions interdependence itself. Only one study examined a form of interdependence as the relationship between parental autonomy support and shared responsibility and found that higher levels of parental autonomy support was associated with higher levels of shared responsibility (Hanna et al., 2012). Shared responsibility, which many of

the reviewed articles mentioned, could be seen as interdependence, where the parties involved take on some responsibilities to work toward a goal together; however, interdependence is more than that (Anderson et al., 1997; Huth et al., 2017; Trudeau et al., 2019).

Huth et al. (2017) proposed a framework of four essential attributes (mutualism, teamwork, alliance, and correlation) that were necessary for cooperative task completion by nurses. Anderson et al. (1997) introduced interdependence as being important for the healthy development of an adolescent with T1D and to ensure parents remained involved in their adolescent's diabetes tasks. Schilling et al. (2006) alluded to interdependence as “pinch hitting” where parents take on an occasional management role to give the adolescent a break from diabetes management. Ivey et al. (2009) implied that trust and proper communication are important for effective T1D management, also key attributes of interdependence. Thus, interdependence appears to be an important component of diabetes management during adolescence and requires additional investigation.

2.4.3 Limitations

This review has some limitations. This study was limited to qualitative and quantitative literature and did not examine the theoretical literature. The inclusion of only those studies that were published in English may have omitted some potentially useful research. The potentially differing nature of diabetes management between non-westernized and westernized countries can influence how families manage T1D in adolescents. A broader review is needed to examine the differences between countries as well as any cultural influences. Many of the quantitative studies were cross-sectional and, therefore, causality could not be established. However, Helgeson et al. (2008) assessed reverse causality in the 3-year longitudinal study and found that only depressive symptoms predicted increased parent responsibility in care. The prospective studies were

generally of short duration, limiting time sensitive changes associated with age. Noteworthy, as well, is that all articles originated in the United States, suggesting a more North American perspective of this concept in the review. This study focussed on research reports from westernized countries where health care for T1D would be fairly similar. Non-westernized countries could have diagnostic and treatment challenges that may interfere with the day-to-day management of T1D. It would be useful in a future review to examine the research related to cultural, geographic, and economic effects on family management of adolescent T1D. The limited number of studies and particularly those qualitative in nature suggest a need to delve more deeply into the conceptual paradigm of interdependence. The studies that were found had smaller sample sizes and varied adolescent age ranges, limiting comparisons of findings.

2.4.4 Conclusion

This study shows that for the most part, parents and adolescents are often in agreement about roles for diabetes care. The role of shared responsibility was seen as being important in effective adolescent diabetes management and is mediated by age. This review uncovered an evident gap in the literature examining the parent-adolescent interaction in T1D management and interdependence. This review clearly indicates the importance of parental support for adolescents to manage their T1D, as well as the need for future research regarding how to best share responsibilities and work towards interdependence in T1D management.

2.4.5 How Might This Information Affect Nursing Practice?

Parents play an important role in supporting their adolescent with management of T1D and it appears interdependence is a concept that requires consideration in planning care. Nurses on the diabetes healthcare team can play instrumental roles in educating the parents or caregivers and adolescents with T1D about how collaboration could be beneficial to overall T1D care and

the detriments of any conflicts that may arise. Observing how the parents or caregivers and adolescents with T1D interact with each other in subsequent visits is an important skill the nurse should have to ensure integration of sharing of T1D management responsibilities is integrated into the overall care plan of the adolescent with T1D. The findings from this integrative review provide support to guide grounded theory research in Chapter three to better understand the experiences of adolescents and their parents, and to explore the concept of an interdependent sharing of responsibility for T1D diabetes management. Findings from such research may inform improved supportive care of adolescents with T1D and their parents.

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CHAPTER 3: MANAGING THE UNMANAGEABLE THROUGH INTERDEPENDENCE IN ADOLESCENTS LIVING WITH TYPE 1 DIABETES AND THEIR PARENTS: A CONSTRUCTIVIST GROUNDED THEORY

3.1 Relationship of Manuscript Two to the Dissertation

The second manuscript is a qualitative analysis of the experiences and processes of interdependence as these apply to the management of T1D in adolescents alongside their parents. This manuscript addresses the main research questions of the thesis by exploring the participants' subjective understanding of interdependence using a constructivist grounded theory approach. The substantive theory that emerged from the analysis of the participants' narratives describes parents' and adolescents' main concern of maintaining glycemic control that had four related interdependent management subprocesses. The result of this research is a model of interdependence representing the substantive grounded theory describing how parents' and adolescents' with T1D interdependently manage optimal glycemic control.

3.2 Manuscript Two

Farthing, P., Bally, J., Dietrich Leurer, M., Holtslander, L., Nour M. A., & Rennie, D. (in press).

Managing the unmanageable through interdependence in adolescents living with type 1 diabetes and their parents: A constructivist grounded theory. *Journal of Pediatric*

Nursing. <https://doi.org/10.1016/j.pedn.200207.016>

Permission was obtained from the publisher to include this revised manuscript in this dissertation.

This manuscript was completed in collaboration with Dr. Bally and Dr. Rennie, my co-supervisors in this dissertation, as well as my committee members Dr. Dietrich Leurer, Dr. Holtslander, and Dr. Nour. My contributions included: conceptualization, conducting the data

collection and analysis, writing of the initial draft, incorporating feedback from Dr. Bally and Dr. Rennie on subsequent drafts and preparing the manuscript for final submission. Drs. Bally and Rennie's contributions included assistance with conceptualization, review, editing, providing critical feedback, and supervision. Drs. Dietrich Leurer and Holtslander provided edits on the final draft. Dr. Nour provided expertise as a specialist in pediatric endocrinology as well as critical feedback and edits on the final draft.

3.3 Abstract

Management of T1D is complex and requires continuous care and monitoring that place many demands on adolescents with T1D and their parents. The purpose of this study was to explore the nature of interdependent T1D management with adolescents and their parents. Using a constructivist grounded theory methodology, 32 open-ended interviews were conducted, transcribed, and analyzed from 11 adolescents aged 10–18 years with T1D and eight parents. The data were coded using three coding phases: initial, focused, and theoretical and this process continued until theoretical saturation was reached. The substantive theory that emerged from the data describing parents' and adolescents' main concern of *Maintaining Optimal Glycemic Control* was *Managing the Unmanageable through Interdependence*. Four related subprocesses were found: *Completing T1D Tasks*, *Attaining Support*, *Balancing Independence*, and *Reconciling Reality*. These subprocesses occurred within the context of the ever-changing *Nature of the Illness*. There is a dynamic relationship associated with interdependence between adolescents with T1D and their parents that varied situationally and by age. Participants also indicated interdependence occurs, or they would like it to occur, with others beyond themselves and the healthcare team to others willing to be involved. Interdependence is a dynamic process and requires ongoing evaluation by healthcare professionals of its function in the daily management of T1D by parents and adolescents. Additional research into of the roles of health professionals and others in promoting interdependence is needed.

Keywords: Type 1 diabetes, interdependence, adolescent(s), parent(s), management of T1D

3.4 Managing the Unmanageable through Interdependence in Adolescents Living with Type 1 Diabetes and their Parents: A Constructivist Grounded Theory

Type 1 diabetes (T1D) is increasing in incidence worldwide (Ogle, et al., 2022). Canada has the eighth highest incidence of T1D globally while the United States is ranked tenth (International Diabetes Federation, 2017). There are approximately 30,000 school age children in Canada who have T1D (Canadian Pediatric Society, 2017). Results from observational studies have shown that adolescence is often a period of deteriorating diabetes management and less controlled blood sugars (Hilliard et al., 2013). Research indicates less than 30% of adolescents with diabetes currently meet their target A1C (Babler et al., 2015; Iina et al., 2021).

Self-care, self-efficacy, and adherence are goals for disease management for adolescents with T1D. However, the importance in sharing responsibility for disease management cannot be underestimated (American Diabetes Association, 2018; Cameron et al., 2018). Some studies have shown adolescents with T1D have better blood glucose management if their parents maintain involvement in their diabetes management (Anderson et al., 1997; Goldenberg & Punthakee, 2013). Thus, ideally in diabetes care, both parent and adolescent are working together or interdependently towards the goal of optimal T1D management.

Since 1959, interdependence theory has been used in social psychology to describe relationships and social interactions within groups (Kelley et al., 2003). As such, the concept of interdependence could have application to enhance family day-to-day management of T1D. For example, Anderson et al. (1997) used the term interdependence relating to T1D management when assessing how the relationship between adolescents with T1D and their parents affected glycemic control. Furthermore, Hanna et al. (2012) tested the importance of interdependence in the relationship between parental autonomy support and shared responsibility (potential factors

in interdependence) in T1D management and found that as parental autonomy support increased, perspectives of shared responsibility by both parents and adolescents also increased (Hanna et al., 2012). Hanna et al (2012) also found that both the perceptions of adolescents and their parents were deemed fundamental for this research. Research has been conducted to investigate the efficacy of self-management in adolescents with T1D (Vloemans et al., 2019); however, there is a paucity of research on the characteristics of interdependence, and the related processes in the day-to-day management of T1D in adolescents.

Therefore, the purpose of this study was to explore the perceived nature of interdependence with T1D management by adolescents with T1D and their parents. To date there are no qualitative studies exploring the concept of interdependence and how it functions in relation to adolescent T1D management. The specific objective of this research was to develop a substantive theory of interdependence grounded in the experiences and social context of adolescents with T1D and their parents. The following research questions guided the research process: How do adolescents with T1D and their parents define and describe interdependence?; what are the experiences of interdependence for adolescents diagnosed with T1D and their parents?; and, what are the processes of interdependence used by adolescents with T1D and their parents? Examining the experiences and related processes of interdependence in adolescents with T1D and their parents could help to advance a more in depth understanding of how interdependence could guide effective pediatric health care in the management of T1D in this population.

3.4.1 Design and Methods

3.4.1.1 Research Design

This study was informed by a constructivist grounded theory approach developed by Charmaz (2014). Charmaz's (2014) research approach assumes a relativist epistemology that acknowledges multiple standpoints, roles, and realities. A constructivist approach adopts a reflexive stance towards background, values, actions, situations, relationships with research participants, and representations of them while situating research in the historical, social, and situational conditions of its production. Constructivist grounded theory helps to develop conceptual foundations that are grounded in data. Specifically, constructivist grounded theory can be used to address gaps in previous research and for the development of substantive theories in new emerging areas of interest. Since there were no qualitative studies exploring what interdependence means to adolescents with T1D and their parents, constructivist grounded theory was an appropriate research design for this study and allowed for investigation of the experiences and processes of interdependence from the perspectives of both adolescents with T1D and their parents (Creswell, 2007; Denzin & Lincoln, 2018).

3.4.1.2 Participants

Participants were recruited from a pediatric diabetes clinic in a western Canadian province using posters, emails, social media, word of mouth, and the assistance of clinic staff (see Appendices B, C, and D). This clinic is the only pediatric diabetes clinic in the province and currently follows approximately 600 children and adolescents living in rural and urban areas of the province. After age 18, adolescents with T1D in this clinic move to the adult diabetes clinic.

The WHO (2022) identifies adolescence as the period in human growth and development that occurs after childhood and before adulthood, from ages 10 to 19. However, due to the

adolescent age range from the pediatric diabetes clinic where participants were recruited, the age range for adolescence in this study was age 10 to 18. So, the adolescent participants had to be clinic attendees with a diagnosis of T1D for at least one year. Parents of adolescent recruits were also asked to be interviewed. All participants had to be able to speak and understand English. Purposive sampling was used to obtain a range of male and female participants who were a variety of ages and ethnicities, and at varying lengths of time since diagnosis of T1D. Ethics approval was obtained from the University of Saskatchewan Behavioural Research Ethics Board (Beh-REB #925) (See Appendix A) and operational approval was gained from the Saskatchewan Health Authority.

3.4.1.3 Data Collection

Prior to any data collection, assent or informed consent was collected from each participant (see Appendices E, F, G, H, and I). Interviews were conducted by the first author at a time convenient to the participants by videoconference (n=27) or teleconference (n=5). Intensive interviews techniques were employed using open ended questions to obtain detailed experiences and perspectives of the participants (Charmaz, 2014). Adolescents and parents were invited to be interviewed separately; however, in three cases, participants preferred that the interviews be conducted with both parent and adolescent in the same room. For those cases, the adolescent/parent was present while the other was being interviewed. All other interviews were completed individually.

The interviews began with demographic information to obtain characteristics of the sample including age of diagnosis and self-report of recent A1C results, followed by briefing about the interview process by the primary investigator (first author) (see Appendices K and L). The recorded interview portion consisted of semi-structured, open-ended questions to ensure the

participants could freely express themselves. The interview guides focused on exploring the help required to manage day-to-day T1D (see Appendices M, N, and O). The guide was revised for subsequent interviews as analysis unfolded to clarify participants' experiences and in light of the emerging themes. Initial and follow-up interviews, lasting 30–90 minutes, were conducted by video conferencing or by telephone depending on the participant's preference. Nineteen participants (eight adults and 11 adolescents) were interviewed once. Second interviews were conducted with 13 participants (seven adults and six adolescents) to follow up with the content from the first interview, to confirm understanding by the researcher, and to develop and expand on the categories emerging from the analysis (Charmaz, 2014). Fieldnotes were written by the researcher before and after the interviews and during analysis to describe the interviewer's personal thoughts and feelings, the setting and environment of the interview, as well as the verbal and nonverbal communication of the participants (Charmaz, 2014; Emerson et al., 2011).

3.4.1.4 Data Management and Analysis

Interview data were recorded and then transcribed verbatim by an experienced transcriptionist who signed a confidentiality agreement (see Appendix J). Transcripts were then checked by the researcher for accuracy and uploaded into ATLAS.ti 8.4.5 Mac[®] for coding and initial analysis. The data were coded into patterns or concepts and this process continued until theoretical saturation was reached (Glaser & Strauss, 1967). The constructivist grounded theory approach includes three coding phases: initial, focused, and theoretical (Charmaz, 2014). For this study, initial coding involved analyzing the data line by line to look for patterns in the data and choosing code words to define and label the data (Charmaz, 2014). The initial coding helped to determine how to proceed with the data as more information about the emerging main concern and the basic social process became evident. The second phase involved focused coding to

process the large amounts of data by analyzing the more frequently occurring initial codes, to determine their adequacy, and to categorize the data more completely (Charmaz, 2014). The third phase, theoretical coding, was completed with what is known from the literature and memo writing to conceptualize how the codes related to each other and integrated into a theory (Charmaz, 2014). To ensure theoretical saturation, 13 participants were interviewed a second time as data collection and analysis progressed thereby refining properties of the emerging conceptual categories and clarifying relationships between the categories (Charmaz, 2014). The emerging categories and themes were examined and refined continuously through discussion with other members of the research team and by reflecting on the research questions. See Table 3.1 for an example of the coding process following the use of Charmaz's three levels of coding.

Memo writing was used as a bridge between focused coding and theoretical coding. Memo writing is essential in grounded theory research to ensure transparency and researcher awareness of any personal biases they may bring to the research, to help identify and expand on categories, and to identify any gaps that may be emerging in the data to help direct theoretical sampling (Charmaz, 2014). Reflexivity was used through the research process as it helped "in recognizing multiple realities, positions, and standpoints and how these shifted during the research process for both the researcher and the research participant" (Denzin & Lincoln, 2018, p. 417; Hall & Callery, 2001). Reflexivity helped to avoid any potential forcing of the data into preconceived codes (Charmaz, 2014).

3.4.1.5 Rigor and Trustworthiness

Charmaz (2014) outlines four criteria to ensure rigor and trustworthiness in constructivist grounded theory research: credibility, originality, resonance, and usefulness. These four criteria were used throughout the research process. Credibility was established by referring to a variety

Table 3.1

Managing the Unmanageable through Interdependence: The Coding Process

Quotations	Initial	Focused	Theoretical
“I have trouble focusing when [my BG] around 15, so at school I ask if I can check my BG quick and then if it is around 15 or higher, I go to a quiet room and let it [BG] come down.” (P#004A)	Blood Sugar Related	Completing T1D tasks	Managing the Unmanageable
“At school a teacher comes and checks my insulin before I take it. At dance if I’m low and eating something my teachers will ask if I’m feeling ok. At school my teacher will also ask if I’m ok if I stop to eat something.” (P#001A)	Activities	Attaining Support	
“Our adolescent needs to be able to care for themselves but I’m going to do as much as I can to take that burden off our adolescent right now, until our adolescent gets used to it” (P#004P)	Dependence	Balancing Independence	
“Like, it’s my disease so I need to manage it by myself, cause...it’s my disease it’s no one else’s, so I think that it should be like if you have the disease you need to manage it on your own. But if you need help, get like, there’s help, like I have help from my mom and dad, and from other people that have known us for a while that if I need help, they, they’re there, but I think that we should manage it on our own.” (P#005A)	Independence		
“Sometimes it’s frustrating like sometimes my sensor won’t connect to my pump for a while and that’s really irritating or. I think I’ll like count my carbs perfectly and then a little while later my blood sugar will be like 15, and I just like things like that are upsetting.” “I think the most challenging part is like when my blood sugar will be high and then I try to make it come down, but it just doesn’t...sometimes I feel very overwhelmed and sad” (P#008A)	Feelings		
“You have a decision to make. This, this is what’s going to keep you alive. If you don’t do your insulin, and you don’t count your	Diagnosis	Reconciling Reality	

carbs, you're going to die. Period. End of story. (P#005P)			
“I'm very concerned about how those costs are going to add up very very quickly for adolescent. Um, it's. I'd like to say I'd like to see more support systems in place, ...everybody always wanted to tell you how to manage the disease and, and that's not how this disease works, it's different for each, each, kid, it's different. And what works for you and your family is not what's gonna work for our family. (P#005P)	Improvements		

of sources (e.g., interviews, memos, fieldnotes) and by maintaining records which also provided an audit trail to illustrate how the data were collected, analyzed, and how the reported findings were based on the narratives of the participants. Originality was ensured through theoretical sampling, the use of constant comparison methods during data collection and analysis, and by referring to the literature as the social processes emerged from the data (Charmaz, 2014).

Originality was ensured through theoretical sampling, the use of constant comparison methods during data collection and analysis, and by referring to the literature as the social processes emerged from the data (Charmaz, 2014). Resonance was ensured by returning to participants as needed to confirm data analysis. As a final step, usefulness was attained by providing a substantive theory of interdependence grounded in the data which may be useful to practitioners who can find application.

3.4.2 Findings

The participants in this study consisted of a diverse sample of eight parents and 11 adolescents with T1D. Adolescents ranged in age from 10 to 18 with a mean age of 15.1 years and a median age of 16 and were diagnosed with T1D for at least one year. Time of diagnosis to the time of the first interview ranged from one to 13 years (see Table 3.2).

Table 3.2*Demographics of Adolescent Participants*

Participant number	Gender	Age	Age at Diagnosis	Location of Home	Most Recent A1C*	Parent Participant Mother/Father/None
001A	F	10	7	Urban	8.2 (147)	Mother
002A	F	13	8	Urban	6.7 (120)	Mother
003A	F	18	13	Urban	7.4 (133)	Mother
004A	M	12	11	Rural	8.0-8.9 (144-160)	Mother and Father
005A	M	17	8	Rural	8.0-8.9 (144-160)	Mother
006A	F	18	13	Rural	U/K	Mother
007A	M	18	16	Urban	6.5 (117)	None
008A	F	16	11	Rural	8.0-8.9 (144-160)	Mother
009A	F	16	10	Urban	U/K	None
010A	M	15	2	Rural	7.3 (131)	None
011A	M	13	9	Rural	9.1 (174)	None

*Participant reported; % (mg/dL)

There was an even distribution of urban and rural participants. The broad range of participants supported the development of the substantive grounded theory titled *Managing the Unmanageable through Interdependence*. The following is a description of the developing substantive grounded theory including: the context of the *Nature of the Illness*; the main concern

of *Maintaining Optimal Glycemic Control*; the basic social process of *Managing the Unmanageable through Interdependence*; and the related subprocesses of *Completing T1D Tasks*, *Attaining Support*, *Reconciling Reality*, and *Balancing Independence*.

3.4.2.1 Context: *The Nature of the Illness*

The findings in this study are interconnected to the larger social context within which the emerging theory was interpreted. The central social context was the experiences of adolescents who have been diagnosed with T1D for at least one year and their caregivers, who happened to be parents in all cases. Their experiences refer specifically to the experience of the diagnosis of T1D, what the nature of management of T1D was like currently for both the adolescents and the parents, and how participants experience interdependence in their disease management.

It became apparent during the initial interviews that T1D was not an easy disease to manage and that tasks are never ending. One adolescent summarized the difficulties managing T1D as, “It’s kind of like having a newborn baby but the baby never grows up...it cries at you in the middle of the night to wake up and feed it and...it never matures, never grows up, never becomes independent” (P#003A). Another adolescent reiterated the complexity and variability of T1D management by stating, “It’s a chronic illness...sometimes I might need some help and that doesn’t mean I’m doing something wrong; it is just the nature of the disease sometimes. People don’t understand that” (P#006A).

According to the participants, many factors influenced the stability of blood sugar readings such as hidden carbohydrates in food, effect of hormones, stress, puberty, exercise, routine, and sleep. Thus, what was determined as the *Nature of the Illness* describes the underlying context for this study that emerged from the adolescents’ and parents’ experiences of

the complexity, unpredictability, and severity of symptoms when trying to maintain optimal glycemic control.

3.4.2.2 Main Concern: Maintaining Optimal Glycemic Control

Most participants in this study alluded to the seriousness of T1D, often referring to situations involving life and death. When asked how they felt about caring for their diabetes, one adolescent commented:

I've always looked at it as...what's the other option? Like, what am I going to do? Not like... die, basically....other people say they could never give themselves a needle...well, I think you would learn how to if you had to...the alternative is to literally die (P#003A).

To stay alive, both adolescents and parents mentioned the importance of A1C values or their blood glucose readings. One adolescent talked about the latest visit to the diabetes clinic, "I have to change settings and stuff there because my A1C was high" (P#011A), while another commented, "the goal is to keep my sugars good" (P#001A). Besides survival, the participants felt that A1C's give them a good indication of how well T1D is being managed.

When asked about the current A1C levels in the demographic portion of the interview, parents and adolescents, before or after stating the A1C, seemed to feel they had to offer explanations as to why the A1C was not in the target range. One parent commented, "[our adolescent's] A1C is not ideal but they have grown 2 inches in the last couple of months and ... there's just so many variables that we can't control" (P#004P). The participants also indicated A1C is the point of discussion every time they have appointments with their diabetes healthcare team. Even though A1C is not the only indicator of glycemic control, the A1C was mentioned more frequently than other indicators as a measure of how well participants are managing their

T1D. Therefore, Maintaining Optimal Glycemic Control includes A1C and blood glucose readings, and was noted as the main concern of the participants.

3.4.2.3 Basic Social Process: Managing the Unmanageable through Interdependence

For the participants in this study, Managing the Unmanageable through Interdependence meant that the plan for managing their diabetes one day, did not necessarily work well the next day. One adolescent summarized the complexity and unpredictability of management by stating:

I think I have like a pretty, like...scientific mathematical logical brain where...if I do $A + B = C$, so...that's the formula I'll follow every day for the rest of my life. Then, one day, all of a sudden $A + B = E$ and you're like umm... 'excuse me' it's suddenly E-squared to the tenth power minus four and you're like...umm...no. This worked 24 hours ago (P#003A).

Interdependence played an important role in how participants managed the dynamic nature of T1D, and both adolescents and parents described it as having a support network. For example, P#003A went on to describe interdependence by stating:

...it's about working as a team and being able to depend on the others around you for support but still being able to have the final say about what happens to you and your body ...[my parents are] good at dealing with, like, more of the emotional aspect. Like, the burnout aspects of it...you never get a break from it...even when it's your birthday or Christmas...it doesn't go away.

Parents saw interdependence as their adolescent sharing the responsibility of T1D management by completing their assigned tasks, communicating effectively, being receptive to teaching, and adapting to changes that constantly come up. Some adolescents also mentioned feeling supported by their entire household.

The level of support given by parents was dependent on age; the younger the adolescent with T1D the more responsibility that was required of the parents and others. A 10-year-old participant with T1D said, “well, my mom tells me how much insulin to take because I don't know the carbs of everything. I usually do the insulin injections myself, but sometimes my mom or dad will do (the injection) in my arm” (P#001A). One parent of a 12-year-old stated, “[our adolescent] relies on us still to count carbs and tell them how much insulin [our adolescent] needs, how much correction [our adolescent] needs, all of that math on top of actually doing the injection” (P#004P). Mid-adolescence, around 14–16 years of age, seemed to be a period of consensus building between parents and adolescents. Communication between the adolescent with T1D and the parent seemed key as one parent suggested “you need to figure out what you want to do and what you want me to do, and then if we agree upon it, then we'll do it” (P#003P). Although most participants thought that T1D is a difficult disease to manage, the older adolescents believed they could be independent while still needing others around for support. For example, one 17-year-old participant-stated:

If you have [T1D] you need to manage it on your own. But if you need help, get...help, like I have help from my mom and dad, and from other people that have known us for a while that if I need help...they're there (P#005A).

Both adolescents and parents spoke of influences on interdependence in T1D management. Smart technology advances in diabetes management (e.g., continuous glucose monitor (CGM), insulin pump) seemed to play a role in how interdependence functions. One parent even included the CGM when describing interdependence as the CGM helped their adolescent with warnings of dangerous blood sugar events before anyone else could notice

behaviour changes due to glycemic excursions, “[our adolescent] knows before any of us know” (P#001P).

Interdependence as applied to T1D management in this study, seemed to differ from the pervasive healthcare system approach of support of self-management for adolescents with T1D. One adolescent with T1D for five years exemplified this difference when saying that they were “told I have to be able to care for myself...[but]...I still want support from others because diabetes is a difficult disease to manage all alone...I sometimes require help from others” (P#006A). One parent summarized the role of interdependence in the management of T1D in adolescents by saying that “type 1’s should [not] be left to fend for themselves and feel alone with no support...absolutely not” (P#001P).

3.4.2.3.1 Subprocesses of Managing the Unmanageable through Interdependence.

As the data were analyzed, four distinct, yet interrelated subprocesses emerged including Completing T1D Tasks, Attaining Support, Balancing Independence, and Reconciling Reality. These subprocesses determined how well T1D was managed in adolescents, in other words, whether they felt that they had optimal glycemic control and were able to manage the unmanageable.

3.4.2.3.1.1 Completing T1D Tasks. Besides the many tasks required for T1D management, no participants felt that they could complete all the T1D management tasks all day, every day, independently. For example, one adolescent stated, “I check my sugar, the hardest part is probably figuring out all the carbs for all the meals...I dial it (insulin) up myself, do the finger pokes myself” (P#004A). When asked about the T1D tasks their adolescent performs in a day, a parent indicated, “[Our adolescent] calculates their own carb to insulin ratio and

administers all their insulin...treats lows when [our adolescent] is low and treats...highs when [blood sugar] is high...and tries to exercise daily” (P#006P). Another parent stated:

We foot the bill for all the supplies but it's up to [our adolescent] to phone and order when they are low on supplies, but [our adolescent] pretty much manages everything on their own. I do an odd check in once in a while (P#005P).

In many cases, as the adolescent moved further away from the time of diagnosis, the more tasks they did independently. For example, one parent of an adolescent with T1D for nine years stated:

And from day one, we were told by the diabetic team that the best thing we could do for [our adolescent] was not manage their disease...so, from the time [our adolescent] came home after initial diagnosis, anytime we needed to make a decision about insulin or anything...we would talk about it, you know as a team, Mom, Dad, [our adolescent]...so [our adolescent] has always been in charge of their diabetes because it's not my disease it's their disease to manage (P#005P).

Similarly, another parent of an adolescent with T1D for one year, stated they were reluctant to give up all control of management, saying “they will have to care for themselves for the rest of their life so I'm giving them a bit of a holiday, I guess” (P#004P). Completing T1D Tasks seems to require much time and attention for both parents and adolescents with T1D.

3.4.2.3.1.2 Attaining Support. While families managed T1D together, help or support from outside the family seemed necessary at times for both the parent and the adolescent with T1D, regardless of age. Both parents and adolescents recognized the importance of the help that is given by others outside of the family in Completing T1D Tasks. Attaining Support for all participants was important to ensure adolescents were safe outside the home, and that others

supporting or in contact with the adolescent were well informed about T1D. Breaks from the complexities of day-to-day management by both parents and adolescents with T1D were mentioned.

One parent was comforted and amazed at the willingness of the teacher to ensure their adolescent was safe during the day at school by "...texting daily and telling me they can tell by [our adolescent's] behaviour if they are high, low, or dropping....no one's ever noticed that before" (P#002P). Similarly, one adolescent indicated that their safety was ensured during school and extracurricular activities by stating:

At school a teacher comes and checks my insulin before I take it. At dance if I'm low and eating something my teachers will ask if I'm feeling ok. At school my teacher will also ask if I'm ok if I stop to eat something (P#001A).

In addition to safety, all participants felt that Attaining Support was only possible if the support was received from those who were well-informed of the intricacies T1D management. One parent indicated this need for well-informed support as follows:

...Not everyone is trained in dealing with highs and lows in type 1 diabetic people. So, they need to be more educated...for [my adolescent's] peers or school, in general how to deal with [T1D]...[people] mixing up type 1 and type 2...Government and people in general, our school system, don't seem to get it [T1D]. Even our police system...why aren't we training these people to look for these [symptoms] and go from there (P#004P).

Attaining Support not only included safe and well-informed help, but both parent and adolescent commented on the critical need to get a break from the day-to-day management of T1D. One parent mentioned:

I need a break without me having to answer what [our adolescent] needs in real time all the time...someone who could prepare a meal and ...tell [our adolescent] this meal that you're about to eat is this many carbs, so that they wouldn't have to text me all the time ... no matter where I am (P#001P).

An adolescent participant stated, “I usually do it myself, just with like carb counting to double check it, [my mom] will sometimes give me a break and do it for me” (P#009A).

Thus, the subprocess of Attaining Support refers to assistance with Completing T1D Tasks by people outside the adolescent-parent relationship, not only for when the adolescent is away from the parent at school, work, or some activity but also when the parent may be away from the adolescent on a vacation or business trip. Those assisting should be trained, preferably in advance, for signs of glycemic excursions particularly, how to treat these symptoms, and even how to operate any necessary equipment. Attaining Support could also include any technology to assist with these tasks.

3.4.2.3.1.3 Reconciling Reality. Type 1 Diabetes is a chronic illness that has no cure and can result in serious health complications and even death if not managed properly. For adolescents with T1D and their parents, reconciling the reality of the disease included coming to terms with their diagnosis of T1D, coping with the stress of having a chronic illness, and incorporating T1D management as a part of their life and daily routines. As one adolescent stated:

Why me? God hates me...everything is awful...it was good for me to be in more control because...in that moment [at diagnosis], it feels like you've lost control of your life and your body a bit...to help manage [my T1D]...helps me regain that sense of... I'm taking control of my life again (P#003A).

Similarly, a parent stated, “trying to be as prepared as possible. So that when life kind of throws you a curveball or whatever...you can deal with it a lot more easily” (P#003P).

Parents also felt grief over their adolescent’s diagnosis, “needing respite” (P#004P), expressing concern about their adolescent being “burnt-out” (P#004P), and feeling frustration with having to change work schedules. The parents mentioned coping in a variety of ways such as seeking counseling, attending wellness clinics, doing research, and assisting their adolescent manage their disease to “relieve some of the parent’s constant worry” (P#005P).

The adolescents with T1D often felt depressed, overwhelmed, stressed, “out of control” (P#002A), and “not normal” (P#001A). One adolescent described how they try to cope with their anxiety:

Stress and pressure from 24/7 isn’t really ever mentioned. I talk to my friends, family, write it out and trouble shoot it and let’s try this and see if it works. [When I’m] stressed I will go play the guitar...while waiting until my correction works...to keep my mind off of it (P#006A).

Others mentioned they reconciled reality by trying to live a life as close to normal as possible and they clearly expressed the need for supportive, non-judgemental communication from parents and healthcare providers including “...proper phrasing and emotional support” (P#003A). As one adolescent stated, “it’s good to have someone, like a cheering section or someone to bounce questions off of” (P#006A).

A few adolescents expressed their satisfaction with the care they were getting from their parents, their healthcare team, and especially others their age who have diabetes. For example, one adolescent stated, “it’s nice to have other diabetic people around my age to talk to and get to know” (P#005A). Thus, Reconciling Reality involved all the techniques and support that helped

both the adolescents and their parents alleviate the stresses and anxieties of living with T1D from the time of diagnosis.

3.4.2.3.1.4 Balancing Independence. In this subprocess two opposites seemed to be held in tension for adolescents: The need for assistance with T1D management from parents and the impetus to be independent. Many of the adolescents with T1D also recognized that they are independent most of the time but still need help sometimes when feeling “low in the middle of the night” (P#006A), for example, or when making treatment decisions like “adjusting basal [insulin pump] calculations and doses” (P#010A). Some adolescent participants commented on how their parents encouraged them to be more independent so they wouldn’t have to “be around their parents 24/7” (P#003A).

Parent participants wanted to see independence in their adolescent’s management of T1D but realized that sometimes this was not possible. The main obstacle was often related to the adolescent’s age. A few parents expressed that even though their adolescents were responsible and able to manage their T1D independently most of the time, they needed reminders and assistance. For example, one parent of an 18-year-old stated:

I don't think [our adolescent] needs that much help... our adolescent is pretty good actually...but our adolescent can get lax too so...most of the time when I say have you done your insulin our adolescent has, like...95% of the time. Our adolescent already has. So it's just me reminding...our adolescent definitely gets reminders...from us...peers or technology (P#003P).

Similarly, another parent of a 16-year-old indicated that their adolescent, “does things themselves...whenever [our adolescent] leaves home...we give them that reminder of what you

take with you...we're constantly kind of saying...we got to make sure there is a backup plan” (P#008P).

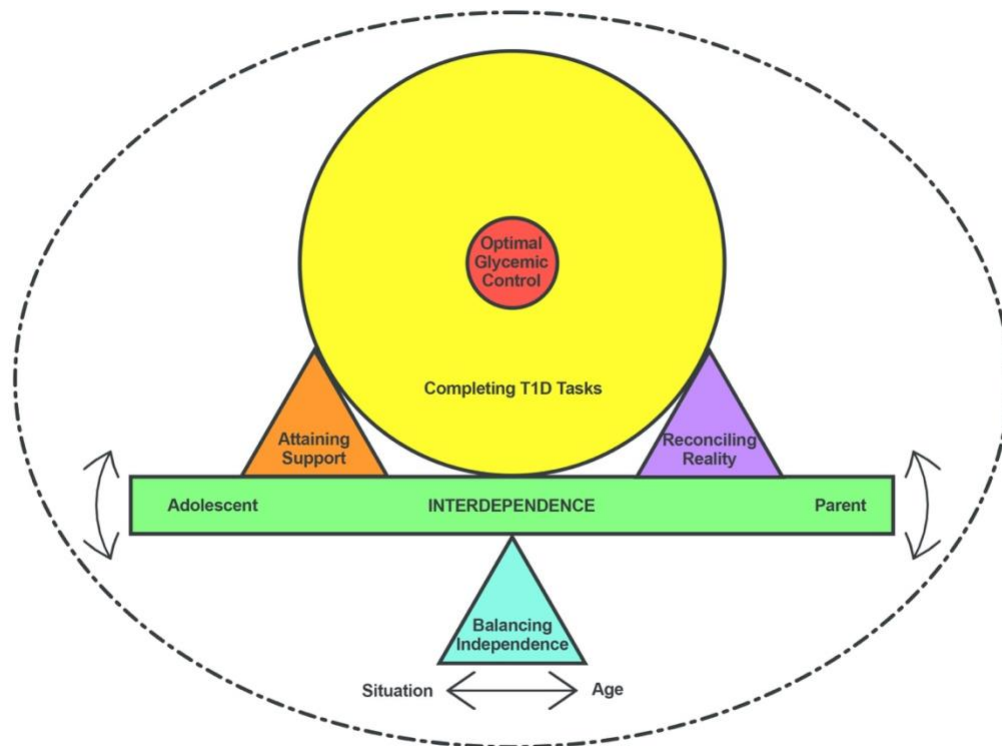
Balancing Independence required the adolescent with T1D to take on more of the responsibility of managing all facets of their disease while realizing that their parents, others, and technology are available to assist, monitor, remind, and encourage them.

3.4.3 Managing the Unmanageable through Interdependence: The Model

The overall substantive grounded theory that was developed from the data in this study is presented in Figure 3.1. Managing the Unmanageable through Interdependence is presented using a model to illustrate the process that the adolescent with T1D and their parents used to resolve their main concern of Maintaining Optimal Glycemic Control (red circle).

Figure 3.1

Managing the Unmanageable through Interdependence



Centered around Maintaining Optimal Glycemic Control is the most predominant of the four subprocesses, Completing T1D Tasks which is represented by a yellow circle. Completing T1D Tasks is the largest shape because this subprocess seems more ubiquitous than the other three subprocesses as the participants were always completing at least one T1D task at any one moment to obtain the goal of optimal glycemic control. Also, Completing T1D Tasks is where most of the parent adolescent interactions occur. The three other subprocesses of this substantive theory are represented as triangles and include Attaining Support, Reconciling Reality, and Balancing Independence. The participants required all four subprocesses to minimize the chaotic effects of the Nature of the Illness on Maintaining Optimal Glycemic Control. The largest outermost area represents the ever-present, complex, and unpredictable context, Nature of the Illness within which Managing the Unmanageable through Interdependence occurs.

Completing T1D Tasks is delicately situated on the platform of Interdependence between the adolescents with T1D on one side and the parents on the other side. The responsibility for Completing T1D Tasks ‘rolls’ back and forth between the adolescent with T1D and their parents but seems to be most stable when they share the responsibilities. Attaining Support from outside the family, represented by the orange triangle and Reconciling Reality of T1D, represented by the purple triangle, both serve as wedges and their positions are interchangeable as they help to balance the completion of T1D tasks and the interdependent relationship between adolescent and parent.

The final subprocess is Balancing Independence, represented by a triangular fulcrum under the Interdependence platform, serves an essential role in balancing interdependence. Naturally, as the adolescent with T1D ages, and requires greater independence, the fulcrum of

the platform moves towards the parent meaning the adolescent now must carry more responsibility of T1D management. Similarly, the fulcrum can shift towards the parent for a particular task situation that needs attention. For example, during a low blood sugar event and simultaneous adolescent incapacitation, the parent would provide a pivotal role in recognizing the adolescent's loss of capacity and provide remedy regardless the age of the adolescent with T1D or the length of time since they were diagnosed. All four subprocesses may be personalized depending on each unique characteristic of the participant and the inconsistent T1D circumstances they deal with from moment to moment in any given day.

In the grounded theory model, Interdependence acts as a platform in which all subprocesses are activated from or on, represents a reciprocal relationship between the adolescent with T1D and their parents, and includes all interactions between adolescents and their parents that offset the unpredictability of the Nature of the Illness. These interactions may be seen as ways the adolescent with T1D, and their parents worked together to share the responsibility of managing T1D to prevent imbalances, thereby, stabilizing Maintaining Optimal Glycemic Control within the centre of Completing T1D Tasks.

An example of the model at work is the management of a 'sick day' for an adolescent with T1D and their parents. Completion of many of the daily T1D tasks may become routine but when an adolescent with T1D is sick, they and their parents will need to align all four subprocesses to ensure optimal blood sugar is maintained. Attaining Support from their parents to complete T1D Tasks like blood sugar monitoring, carbohydrate counting, and insulin dose calculations may be essential. Reconciling Reality becomes a necessary factor in Maintaining Optimal Glycemic Control when, for example, their parents ease the stress of missing school by communicating with teachers and collecting homework for their adolescent without being asked.

Then, Balancing Independence also becomes a necessary component when the adolescent realizes and accepts that the help from their parents is necessary to manage blood sugars when an illness is impacting their blood sugar levels. In this example, all four subprocesses factor into the difficult task of managing blood sugars effectively while ill, where engagement in interdependence ensures a steady balance.

3.4.4 Discussion

Interdependence was not easily defined by many of the participants; but those who tried described interdependence as teamwork, mostly between themselves, and developing a network of support in all areas of T1D management. Although many adolescents in this study felt that their parents were the most important members of their team, they also experienced interdependence through others. Parent participants experienced interdependence when their adolescent demonstrated responsibility with T1D management and was receptive to learning.

The data from the participants in this study suggest that as adolescents with T1D age and mature they can take on more of their management independently; however, no participants saw the management of the disease as a completely independent endeavour. This developing theory suggests an ongoing process that adolescents with T1D and their parents are working with from the beginning of the T1D diagnosis. Most participants were very satisfied with the support they were receiving from the healthcare team but wanted more options for qualified support in the community.

The literature rarely mentions interdependence in relation to T1D management with adolescents. Anderson et al., (1997) found better metabolic outcomes for 10–15-year-old adolescents with T1D when interdependence was applied to parents' home management of adolescents with T1D. Trudeau et al. (2019), in a small study of two brothers with T1D,

suggested interdependence as a final stage of diabetes self-management and saw interdependent management as mainly independent management with parents and healthcare practitioner's guidance as needed. While both Anderson et al. (1997) and Trudeau et al. (2019) mentioned interdependence in their studies, Trudeau et al. (2019) saw interdependence as a final stage of diabetes self-management during late adolescence. The current study adds a novel and enhanced understanding, suggesting interdependence is an ongoing and complex process.

In a cross-sectional study of 87 parents and adolescents with T1D (age 12–17) Hanna et al. (2012) tested a model of interdependence between parental autonomy support and shared responsibility. They found that as parental autonomy support increased, shared responsibility for both parents and adolescents also increased. However, parents reported this shared responsibility decreased with increasing age of the adolescent while adolescents reported that parental autonomy support decreased with increasing age. The findings in the present study are unique in that the participants seem to view interdependence as something that was necessary from day one of diagnosis, not as a final stage of self-management to work towards. Also, the present study provides new insight as the participants indicated interdependence occurs, or they would like it to occur, with many others beyond their parents involved.

In this study the completion of T1D tasks were described as dynamic, numerous, complex, and crucial to the overall current and long-term health of the adolescent with T1D. It was of utmost concern for participants and needed to be completed continually and consistently to maintain optimal glycemic control. Coffen (2009) indicated the underestimation of the effort and difficulty required to manage T1D by comparing its complexity to “flying an aircraft” and presented a task analysis that details the demands of a T1D regimen that contains more than 600 tasks. Coffen's (2009) itemized list provides a clear perspective, supported by Hung et al.'s

(2020) research, on why there is sometimes lack of motivation, and struggles with adherence, when these items are a constant lifelong requirement of an adolescent with T1D. It appears an important part of interdependence is a sharing and monitoring of T1D tasks with others.

Adolescent participants in this study indicated that they needed help to complete their T1D tasks in a variety of ways and in varying degrees from parents, other family members, coaches, their healthcare team, friends, and at school. Researchers from around the world have studied how metabolic control and movement towards independent self-management are improved by support from family and friends (Alhaidar et al. 2020; Anderson et al., 2009; Lee et al., 2019; Strand et al., 2018). The above-mentioned studies do not specifically address which age dependent tasks the adolescent with T1D needs support with. For example, the present study indicates that some younger adolescents with T1D want help with tasks such as insulin injections and carb-counting, while older adolescents with T1D would prefer assistance with basal calculations and the financial burden of T1D management. Researching age-appropriate support could provide information to help improve glycemic control for adolescents with T1D (Coffen et al., 2009).

The subprocess of Reconciling Reality demonstrates the importance of learning to cope with the initial stress of diagnosis and then with the looming pressures of daily T1D management to avoid injury, complications, and death. The present study is unique in that it did not have any questions pertaining to fear of injury, complications, or death, yet several of the participants mentioned their fears, particularly of death as part of sharing their experiences. The notions of death and dying were expressed when participants were reflecting on the diagnosis of T1D, when discussing hyper- and hypoglycemia, and as a measure of how well they were managing T1D.

Several researchers looked at fear of hypoglycemia and hyperglycemia, but no research was found specifically about fear of death in adolescents with T1D and their parents (Di Battista et al., 2009; Shepard et al., 2014; Viaene et al., 2017). As this was a pervasive finding in the current study, the topic requires additional investigation to add to the existing literature.

Lastly, the conflict between promoting independent management and providing/needing assistance cannot be overlooked and was subsequently designated as the subprocess of Balancing Independence. Although the participants seem to agree that becoming more independent as the adolescent with T1D transitions towards adult care is a goal, none indicated that this transition should be without support or training. Adolescents appear to need help to manage their T1D independently. Adolescence has been found to be a period of deteriorating diabetes management and less controlled blood sugars (Hilliard et al., 2013), and it has been shown that adolescents who independently manage their T1D have higher A1C values (Nakamura et al., 2019). Research confirms the concern of the participants that supervision and overseeing care are still needed as the adolescent with T1D ages (Foster et al., 2016, p. e328). Improved T1D management results when parents provide emotional support, encourage independence, and have open communication (Lancaster et al., 2015; Young et al., 2014).

An interdependent approach to diabetes management could be an important way to optimally manage T1D particularly during the challenging transitional stages of adolescence, and early adulthood. Previous to this study, there was limited research exploring the concept of interdependence and how it functions in relation to adolescent T1D management from the perspective of adolescents with T1D and their parents (Anderson et al., 1997; Hilliard et al., 2013; Ivey et al., 2009). There is some T1D self-management research on parental involvement in T1D management, however most of the current research is mainly quantitative and mostly

focusses on the adolescents' connection with the diabetes healthcare team (Guo et al., 2011; Majumder et al., 2017; Rausch et al., 2012).

To our knowledge, most of the transition to adult healthcare system research focusses on the young adult with T1D and the healthcare system (Helgeson et al., 2014; Hilliard et al., 2016; Mistry et al., 2015). The limited interdependence research is more focussed on the adolescents with T1D and their relationship with their parents. Where there are strong interdependent relationships with mutual respect and trust it may be expected that T1D management would be more successful during transition into adulthood.

3.4.5 Research and Practice Implications

This study has implications for nursing education, practice, and research. The model illustrates how difficult maintaining optimal glycemic control by families can be due to a myriad of factors that cannot be controlled every time, all the time. Reassuring families that T1D is a difficult disease to manage, and providing anticipatory guidance focused on the concept of interdependence and subprocesses could potentially lead to better long term T1D management. Nurses, especially those who work in schools or pediatric diabetes clinics, can utilize the model of interdependence to strategize ways to individualize and personalize the care and, with the help and approval of parents and their adolescents with T1D assist with the development of a support network. Generally, from the moment of diagnosis children and adolescents with T1D and their parents are taught to move towards self-management of their diabetes. It may be prudent to consider a slightly altered approach to ease into self-management and ensure there is an understanding that support is required due to the chronic condition, not as a punitive action due to lack of ability to self-manage. For example, at first follow-up appointment after T1D diagnosis, if there are signs that the adolescent with T1D is ready to assume more independence

in the management of their disease then that should be discussed. The nurse needs to help the adolescent balance independence by helping the adolescent with T1D and their caregivers understand that they are not alone as they adjust to their new situation, they can care for themselves, the caregivers can help, the clinic is there to help, there is technology that can help, and there are even specially trained dogs that can be obtained to help. At subsequent clinic appointments, the nurse can help train the caregivers how to support the adolescent with T1D with proper communication such as by encouraging and offering assistance instead of questioning or criticizing how the adolescent is performing the necessary tasks.

Furthermore, there is a dynamic relationship associated with interdependence between adolescents with T1D and their parents that varies situationally and by age and time from diagnosis. Researching age-appropriate support could provide information to help improve glycemic control for adolescents with T1D. It would be important to consider integrating the concept of interdependence in future revisions of current Diabetes Canada guidelines for the care of adolescents with T1D. Another important consideration to build, support, and encourage interdependence is to ensure all nurses in their undergraduate and continuing education are given a basic understanding of the complexities of T1D management as well as an awareness of the technology that can be involved to help to manage T1D.

The current study suggests the need for investigation into the role of non-family members in supporting parent-child interdependence in managing adolescent T1D. How best to encourage independence while still being supportive could be a topic of future study. Future research could expand the qualitative understanding of the experiences of interdependence by including participants in other healthcare settings, older age groups, and more diverse households. Quantitative research could be conducted to examine any relationship that may exist between

blood glucose/A1C and interdependence. Also, investigation into the importance of interdependence and the subprocesses of interdependence using quantitative approaches would help to validate the model. Future research could also be done to explore how the requisite time and attention needed for interdependence could be provided by someone or something other than a parent. Can others support the adolescent with T1D, not just a parent? Could technology, a peer, sibling, medical team member, or others in the community be the interdependent support so normal growth and development (movement away from parent) can be facilitated? This could help ameliorate any barriers imposed by social determinants of health for adolescents who may not have consistent access to one or both parents and for parents who do not have the time/opportunity to provide the support required.

3.4.6 Limitations

This was the first study to investigate interdependence through a qualitative lens in the context of adolescents with T1D and their parents, adding important findings to the existing literature. An additional strength of this study was the use of the constructivist grounded theory methodology which enabled an interpretive understanding of the experiences of adolescents with T1D and their parents and facilitated the development of a substantive theory of interdependence grounded in those experiences.

The study has some limitations when interpreting the findings. Purposive sampling was used to invite participants to the study. Theoretical sampling was limited due to the limited number of participants who volunteered after several calls for participants. However, it should be noted that the sample for this study was representative for sex and geographical location, but predominantly Caucasian. In addition, the sample was obtained from one pediatric healthcare centre which may limit the participants' perspectives, experiences, and findings. Also, due to the

homogeneity of the Caucasian participant sample in this study, we could not explore differences in interdependent management that might be influenced by other dominant cultures, by single family or blended households, different healthcare systems or health providers, or differences due to other social determinants of health (e.g., ethnicity, socioeconomic status).

The theory is presently limited to information about T1D management of adolescents living in two-parent households, with the exception of one household in which the parents were divorced but shared parenting. There were four parents who did not participate in the study limiting comprehensive examination of the perspectives of all parents of adolescent participants. The substantive grounded theory is an interpretive rendering of the data and the researcher's subjectivity needs to be acknowledged as other understandings of the data may exist. The participants are not racially diverse nor is there diversity in the number of parents who support the child. The age range of the participants as well as the years since T1D diagnosis could have impacted the analysis as the need for parental support likely varies markedly by age of the child and years since diagnosis. Also, the A1C was collected for background information only, so it may have been more useful to have this information from medical records as not all participants could recall their most recent A1C. However, these findings offer new insights, enhance knowledge, and will likely have theoretical reach or transferability. Conceptualization and conveying what is meaningful from these findings is up to the reader which meets Charmaz's trustworthiness criteria of resonance and usefulness (Charmaz, 2014).

3.4.7 Conclusions

The substantive theory of Managing the Unmanageable through Interdependence that emerged from the data in this study indicates there are four subprocesses (Completing T1D Tasks, Attaining Support, Reconciling Reality, and Balancing Independence) that adolescents

with T1D and their parents use to resolve their main concern of Maintaining Optimal Glycemic Control. The participants require all four subprocesses to minimize the chaotic effects of the Nature of the Illness on Maintaining Optimal Glycemic Control. There is a dynamic relationship associated with interdependence between adolescents with T1D and their parents that varies situationally and by age and time since diagnosis. Participants also indicated interdependence occurs, or they would like it to occur, with others beyond themselves and the healthcare team, to others who are willing to be involved. Current practice in the care of adolescents with T1D is encouragement towards independence and self-reliance in disease management. Findings from this study suggest that adolescents and their parents benefit from an interdependent relationship that includes the support of others within their environment as needed. Interdependence may extend beyond the family environment and additional research is needed to enhance the understanding of the parameters of interdependence and to determine what effect it has on glycemic control.

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CHAPTER 4: PERCEPTIONS RELATED TO DEATH IN ADOLESCENTS WITH T1D AND THEIR PARENTS DURING THE MANAGEMENT OF TYPE 1 DIABETES: A THEMATIC ANALYSIS

4.1 Relationship of Manuscript Three to the Dissertation

The third manuscript included in this dissertation is a reflexive thematic analysis of the data obtained from the primary grounded theory study. Data emerged during the initial study describing feelings of fear related to dying as a result of living with T1D. As these findings were not the focus the primary study, the frequent occurrence of such experiences necessitated a comprehensive re-exploration of the data using a reflexive thematic analysis. This manuscript aligns with and supports the dissertation by presenting these findings which show that adolescents with T1D and their parents not only need assistance with managing T1D in a variety of ways, but also require support to cope with the stress of diagnosis and the threat of death that is ever present.

4.2 Manuscript Three

Farthing, P., Bally, J., & Rennie, D. (2022). Perceptions related to death in adolescents and their parents during the management of type 1 diabetes: A thematic analysis.

This manuscript will be prepared for submission for publication to a peer-reviewed journal. This manuscript was completed in collaboration with Drs. Bally and Rennie, my co-supervisors in this dissertation. My contributions included: conceptualization, conducting the data collection and analysis, writing of the initial draft and incorporating feedback from Drs. Bally and Rennie on subsequent drafts, and preparing the manuscript to meet journal guidelines for submission. Drs. Bally and Rennie's contributions included assistance with conceptualization, review and editing, providing critical feedback, and supervision.

4.3 Abstract

Type 1 diabetes (T1D) is associated with a substantially increased risk of premature death compared to the population without T1D. The experiences and perceptions of fear of dying have not been well studied in adolescents with T1D and their parents. The purpose of this study is to examine the perceptions of fear facing the possibility of death while managing T1D. A reflexive thematic analysis was used to examine the perceptions related to death of parents and their adolescents with T1D who participated in a primary grounded theory study of interdependence in T1D management. The transcripts of 32 open-ended interviews from 11 adolescents aged 10–18 years with T1D, as well as eight parents were examined using reflective thematic analysis. Following coding and creation of initial themes, three final themes were generated from the data through reflexive engagement: 1) Facing the Reality of Death, 2) Fearing the Highs and Lows, and 3) Finding a Way through Fears. The participants in this study indicated they see death as a consequence when they fail to optimally manage T1D. Additional investigation to better understand and explore fear of death in adolescents with T1D and any fear parents may have of the death of their adolescent with T1D. Future research in this area may lead to interventions that can be used to support adolescents and their parents in pediatric hospital and community settings.

Keywords: Type 1 diabetes, adolescent(s), parent(s), management of T1D, fear, death

4.4 Perceptions Related to Death in Adolescents and their Parents during the Management of Type 1 Diabetes: A Thematic Analysis

There is a substantially increased risk of premature death associated with T1D compared to the population without T1D (Lind et al., 2014; Morgan et al., 2015). Even with optimal glycemic control, people with T1D can have a risk of death. Lind et al. (2014) found that the risk of death from any cause was twice as high for patients with T1D when compared to matched controls. The increased mortality in people with T1D under age 50 is mainly due to acute complications of diabetes including hypoglycemia, diabetic ketoacidosis (DKA), and sudden unexpected death, which is referred to as ‘dead in bed’ syndrome (Lind et al., 2014; Secrest et al., 2010). In a recent grounded theory study of parents and their adolescents with T1D, Farthing et al. (in press) found several of the participants mentioned their fears, particularly of death, as part of sharing their experiences with T1D management. Currently, there is limited research literature examining adolescents’ with T1D perceptions related to death. Research in this area could help to improve methods of assessing for and coping with, fears related to the topic of death in adolescents with T1D and their parents.

4.4.1 Background

Even though there are concerns regarding long-term complications associated with T1D possibly resulting in death, the concerns and fears found in the literature surrounding diagnosis of T1D focus on avoiding hypoglycemia and ketoacidosis (Driscoll et al., 2018; Wherrett et al., 2018). Hypoglycemia (low blood sugar) for people with T1D hypoglycemia is a BG level < 4.0 mmol/L (Yale et al., 2018). While some people with diabetes may have asymptomatic hypoglycemia, the most common symptoms of hypoglycemia are neuroadrenergic symptoms associated with mild hypoglycemia such as trembling, sweating, increased heart rate, and

anxiousness (Wherrett et al., 2018). More severe hypoglycemia may be associated with neuroglycopenic symptoms such as confusion, loss of consciousness, seizure, and death (Yale et al., 2018). How often hypoglycemia occurs and how severe it is can result in significant fear of future hypoglycemia (Gonder-Frederick et al., 2006).

Diabetic ketoacidosis (DKA) is a serious life-threatening complication of diabetes and is the leading cause of mortality in adolescents with diabetes (Wherrett et al., 2018). DKA occurs as a result of the metabolic effects of a lack of insulin required for glucose uptake into liver, muscle, and fat. The result is a cascade of events in the liver including increased gluconeogenesis, glycogenolysis, lipolysis, and ketogenesis leading to metabolic acidosis, dehydration, and electrolyte derangements. If this cycle of events is not corrected with insulin, the resulting ketoacidosis may result in hypotension, shock, or death (Geffken et al., 2008; Wherrett et al., 2018). While prevention, recognition, and early treatment of DKA are important, sometimes there is no clear reason for DKA. Some common causes of DKA include insulin omission, illness, surgery, injuries, drug interactions, intoxication, infection, infarction, and stress (Geffken et al., 2008; Goguen & Gilbert, 2018; Wherrett et al., 2018).

Research has shown adolescents with T1D are more likely than their peers to have problems with psychological functioning; however, most of the related research is focussed on depression and the stress and anxiety that come with optimal glucose management (Helgeson et al., 2008; Herzer & Hood, 2010; Whittemore et al., 2002). Just as is seen in other chronic diseases, such as asthma and cancer (Bitsko et al., 2014; Hølge-Hazelton et al., 2016), anticipatory worry about negative outcomes can increase during adolescence and this stress has been shown to cause alterations in T1D management (Ersig et al., 2015). For example, adolescents may adjust their insulin doses to prevent nocturnal hypoglycemia (Ersig et al., 2015).

Fear of hypoglycemia, particularly nocturnal hypoglycemia, has been shown to cause psychological distress for parents of adolescents with T1D (Barnard et al., 2014). As such, despite death being uncommon for those with T1D, adolescents and their parents may have stress and fear about this occurring. Stress, worry, sadness, and anxiety can negatively impact glycemic control (Herzer & Hood, 2010; Rechenberg et al., 2018).

The experiences of fear of death associated with T1D have not been well studied in adolescents with T1D and their parents. There is research into fears of managing diabetes such as the fear of hypoglycemia or fear of needles that adolescents with T1D and their parents may have (Shepard et al., 2014). Qualitative perspectives of the nature of these fears is limited. In our recent grounded theory study examining interdependence in T1D management in adolescents with T1D and their parents (n=19), we noted that many of the participants mentioned their fears, specifically of the reality of death, as part of sharing their experiences in managing T1D (Farthing et al., in press). These perceptions included fears associated with hyperglycemia and hypoglycemia.

The purpose of this reflexive thematic analysis was to explore the perceptions of adolescents with T1D and their parents, of fears related to the possibility of death in adolescents with T1D. The analysis is based on data from a primary grounded theory study about interdependence and managing T1D during adolescence. The guiding research question for this analysis was: what are the perceptions of fear related to death associated with the diagnosis and management of diabetes in adolescents who have T1D and their parents?

4.5 Methods

The data for this secondary analysis was collected as part of a grounded theory study exploring the experiences of interdependence in adolescents with T1D and their parents in a

western Canadian city (Farthing et al., in press). A secondary analysis approach can be used to investigate new research questions that emerge but are not addressed in the primary research study (Heaton et al., 2019; Thorne, 1998). Through the participants' descriptions of interdependence and how they felt about the diagnosis of T1D, rich data emerged regarding feelings of fear and facing the reality of death that seemed to be incorporated into the ongoing management of T1D for many of the participants. The importance of these experiences necessitated a re-exploration of the data to capture this phenomenon that was not fully understood in the initial grounded theory analysis. Therefore, using an inductive approach, Braun and Clarke's (2006, 2019) reflexive thematic analysis was applied to the data. A reflexive thematic approach uses a researcher's knowledge and skills in interpreting the codes found in the data to develop themes. In this reflexive thematic analysis, the researcher noted the participants' frequent mention of the words "die", "death", "fear", "scared", "afraid", "anxious", "stress", and, at times, observed emotional upset as they were answering the interview questions during the original study. The words indicating stress and fear were most often mentioned when answering questions about how parents and adolescents with T1D managed the chronic illness, or when discussing particulars associated with the diagnosis of T1D (Braun & Clarke, 2006, 2019).

4.5.1 Sample/Setting

In the primary study, purposive sampling was used. Participants were recruited from a pediatric diabetes clinic using posters, emails, social media, and the assistance of staff at the clinic. This clinic is the only pediatric diabetes clinic for a western Canadian province and currently follows approximately 600 children living in both rural and urban areas of the province. The inclusion criteria consisted of the following: adolescents aged 10-18 years who were diagnosed with T1D for at least one year and ideally had a parent or guardian that could

participate, as well; parents could be of any age and participants could be of any ethnicity but had to be able to speak and understand English. The inclusion criteria were kept broad to ensure that a wide range of adolescents from varying backgrounds and experiences would be eligible for the study. Initial purposive sampling process is reported elsewhere (Farthing et al., in press).

4.5.2 Data Collection Procedures

This study was approved by the University of Saskatchewan Behavioral Ethics Board (Beh-REB #925) and by the Saskatchewan Health Authority. Prior to any data collection, assent or informed consent was collected from each participant. Sample questions from the interview guides are included (see Appendices M, N, and O) and for more detail on the data collection and interviews please see the article in which the primary study is described (Farthing et al., in press).

4.5.3 Data Analysis

Recorded interviews were transcribed verbatim and checked for accuracy by the primary researcher. The recordings and transcribed files were then stored on a password protected external hard drive. Originally the data was coded line by line and entered into Atlas.ti™ program. Braun and Clarke's (2006, 2019) reflexive thematic analysis approach was applied to this data and consists of six phases, beginning with familiarization of the data. First, the data were collected, transcribed, and the researcher listened to the audio recordings repeatedly and read and re-read the transcripts making notes of initial ideas before moving to the second phase of initial code generation and organizing the pertinent data for each code. In the third phase, the initial codes that were generated by the primary researcher were then organized into themes and subthemes. Phase four involved review of the themes by the primary (PF) and secondary (JB, DR) researchers and was completed using constant comparison relating the themes back to the

data. The main thematic categories were developed from the data with the use of participants' words as much as possible. Phase five included defining, refining, and consolidating each of the three main themes. In phase six, the final analysis supported the researchers in relating the themes back to the data and the research question to ensure a robust analysis (Braun & Clarke, 2006, 2019).

4.5.3.1 Rigor

For this secondary analysis, Lincoln and Guba's four criteria for trustworthiness; credibility, dependability, confirmability, and transferability were used to ensure a reliable construction of the realities of the participants (1985). Credibility of the findings was established through in-depth analysis of the data and by spending adequate time in the initial study to understand as much as possible about T1D before meeting with participants. Professional and personal experiences helped to establish good rapport and to ensure results were true representations based on the narratives of the participants. Also, the researcher regularly checked in and debriefed with the co-supervisors throughout the research process. Dependability was ensured through lengthy engagement with the data over several months and by maintaining detailed records which provided an audit trail. Confirmability was ensured using constant comparison methods during data collection and analysis. Transferability was ensured as much as possible by recruiting participants from a province-wide clinic resulting in thick description of the data in this thematic analysis.

4.6 Findings

4.6.1 Sample

The participants in this study consisted of a diverse sample of eight parents of adolescents with T1D and 11 adolescents with T1D who ranged in age from 10–18 with a median age of 15.1

years. Adolescents were diagnosed with T1D for at least one year and the range of years since diagnosis to the time of the first interview varied between one and 13 years. There was an even distribution of urban and rural participants, and most parent participants were mothers. The majority of participant interviews were conducted by videoconference (n=27) with a few by teleconference (n=5).

4.6.2 Themes

The findings of this study reflect the experiences of living as an adolescent with T1D and the views of their parents. Feelings of fear and being afraid were mentioned often and included the fear of death, as well as other fears associated with T1D. While participants used a variety of terms such as “fear”, “feeling scared”, or “feeling afraid”, for the purposes of this analysis, these terms will be used synonymously as feelings of fear. The fear of death was mentioned regularly by the adolescent and parent participants when discussing T1D management and when recalling the diabetes diagnosis. Other fears mentioned by both parents and adolescents were fears of high and low blood sugars, of needles, and of losing the ability to cope with the fear of living with a chronic illness where death is a possibility. There were three themes that emerged from the data: 1) Facing the Reality of Death, 2) Fearing the Highs and Lows, and 3) Finding a Way through Fears.

4.6.2.1 Facing the Reality of Death

The mention of death was intriguing as some adolescents with T1D and their parents mentioned death as a matter-of-fact measurement of how well they were managing their T1D. Some parents welled up with emotion when recalling the adolescents’ T1D diagnosis. The emotion was evident even over the telephone (n=5) by their wording and tone of voice but also for those participating in face-to-face interviews (n=27), their body language, and for some,

holding back tears, indicated that death was an ongoing concern. Several parents talked very openly about their adolescent dying if they did not help to manage their adolescent's T1D. One parent said, my adolescent "would die, no for real, they would be dead" (P#004P). Some parents encouraged their adolescent with T1D to be more cooperative in day-to-day management by being forthright about the possibility of death. For example, one parent stated:

This, this is what's going to keep you alive. If you don't do your insulin, and you don't count your carbs, you're going to die. Period. End of story...you have two decisions, you can lay down and die, or you can put one foot in front of the other and figure this...out (P#005P).

Adolescents with T1D were aware of the reality of death, were less emotional, and were well aware of what events could precipitate death. One adolescent stated, "self-managing is keeping myself alive, being my own doctor, my own patient, doing my own injections, like carb counting. Getting the stuff that I need when I need it...making sure I don't die or pass out" (P#005A). One adolescent described an incident where their insulin was going to be confiscated during school time and exclaimed, "Do you want me to die (P#002A)?" Another adolescent with T1D was very aware of what tasks were necessary to stay alive, especially the requirement for daily administration of insulin by themselves, saying "Caring for diabetes is...I always looked at is as like what's the other option? Like what am I going to do? Not like, die, basically...the alternative is to literally die" (P#003A)! Both adolescents with T1D and parent participants displayed varying responses, some seemed detached, disengaged, absent, or matter of fact whenever they mentioned death, while others showed responses like shock and crying.

When recalling the T1D diagnosis event, most participants, especially the parents, expressed distress through their body language, and tone of voice, with some holding back of

tears indicating that diagnosis seemed like an unresolved concern. “It's probably the most scared I've ever been as a parent...we were afraid that, you know, she might not make the night” (P#008P). Similarly, some of the adolescent shared recollection of being scared at that time. “I felt scared when they told me I had diabetes. I had no idea what diabetes was” (P#001A).

Facing the death of one's child is not something most parents have to conceptualize nor experience; however, the parents of adolescents with T1D confront this reality upon diagnosis and every subsequent day after that. Some parents seemed free to discuss this reality quite openly while others fought back tears. Adolescents varied in their conceptions of facing death from avoiding death as a motivation to manage their T1D effectively to feeling afraid some of the time. However, for most participants, facing death was an ever-present reality that required coping mechanisms.

4.6.2.2 Fearing the Highs and Lows

Glycemic excursions in people with T1D have the potential to bring about undesired and potentially lethal symptoms and outcomes (Wherrett et al., 2018). Hyperglycemia and its potential consequences were mentioned most frequently when the parents were discussing the T1D diagnosis of the adolescent. For example, one parent recalled the day their child was diagnosed with T1D and indicated their adolescent's blood sugar was very high and the parent was not sure their adolescent was going to survive the night.

All participants expressed concern and worry about hyperglycemia, acknowledging that it was associated with DKA and hospitalizations. When the participants mentioned this worry over high blood sugar, they indicated it was because of how the adolescent with T1D felt, that is, how high blood glucose affected the adolescent physically and emotionally. Often a parent participant

could tell by the behaviour of their adolescent with T1D that the adolescent had hyperglycemia.

One parent stated that their adolescent:

Has no concept of a high even when it's in the high 20s, they know why to avoid high blood sugar, but when I talk to them about the health reasons to avoid high blood sugar, they get anxious...it is rough for our adolescent to hear...(parent starts crying) (P#002P).

Some adolescents indicated they feared poor performance in school and their activities when their blood sugars were too low or too high. One adolescent mentioned how frequent high blood sugars would affect their A1C, and another mentioned how difficult it was to “concentrate” to do things like writing tests:

When I have high blood sugar I will try and bolus it and try and get my blood sugar back to the zone and uh mostly I just try and go on with my day, but there are times where...I need a break. I need to take a few minutes break from people and from everything. Not ...think, but...you can't make yourself feel better. You need time. Like having a nap helps usually after that I feel a bit better but usually I'm too busy for that (P#010A).

In these cases, the participants mentioned high blood sugar as something to be avoided as negative outcomes usually followed a high blood sugar reading. Some of the negative outcomes expressed included, not doing well on exams, feeling terrible afterwards, and feeling criticized, disbelieved, or judged unnecessarily as having caused the hyperglycemia.

Although hyperglycemia was something participants wanted to avoid, both parents and adolescents with T1D mentioned more often being “afraid” and “scared” of hypoglycemia. One parent mentioned they noticed their adolescent would get “really shaky and...super scared” and then have “anxiety about going low” (P#002P). Another parent mentioned their adolescent purposefully ran their blood sugar high while exercising because of the “fear of going low”

(P#006P). A parent mentioned their fear of death when they received a notification on their cell phone from their adolescent's glucose monitor that their adolescent had a low blood sugar reading, stating "I get the alert and then I hear nothing, so I'm texting and phoning my [adolescent]...that's stressful" (P#006P).

Adolescents also expressed concern about hypoglycemic events. One adolescent mentioned being fearful of being alone when having low blood sugar, "who would notice me sweating?" (P#007A). While another adolescent with T1D admitted that "lows are worse than highs for me" based on that adolescent's inability to get anything done (P#011A).

Both parents and adolescents expressed concerns about both high and low blood sugar excursions, fearing a lack of effective response from others. One parent mentioned their concern with the general lack of knowledge about T1D in the community, expressing fear at how their adolescent may be treated by others "[they think] these people with T1D may be drunk, or high, or whatever but they're having high or low blood sugar" (P#004P).

Another parent stated, "I was told if [my adolescent] had a 'low' at school, if they found him on the floor, passed out, they wouldn't even be administering his emergency glucagon...I find that more frustrating than anything" (P#005P). Adding to the lack of confidence some participants have with some community members' knowledge of T1D, an adolescent participant said:

Unfortunately every time (four times) we've gone to emerg (since diagnosis due to hyperglycemia)...in none of the situations were the doctors and nurses very educated on being diabetic (having T1D)...they don't know what to do...they've just been kind of like, well, you know, drink lots of fluids they'll just say something weird, [so] it doesn't seem like a lot of people are educated (about T1D) in the ER (P#008A).

Dealing with high and low blood sugars is something adolescents with T1D and their parents do regularly as part of managing T1D. Fear of glycemic excursions is something the participants in this study mentioned regularly when discussing T1D management. The adolescent and parent participants had similar concerns about hypoglycemia, with the main concern being fear of dying. Parents seemed to fear death caused by hyperglycemia, not only in acute situations like at diagnosis or in DKA episodes, but also the long-term consequences of hyperglycemia that may cause a premature death. Adolescents expressed those fears as well but also indicated they feared hyperglycemia because of how terrible they feel during and following high blood sugars and because they feared performing poorly at school or during activities due to hyperglycemia.

4.6.2.3 Finding a Way through Fears

Finding a way through their fears was challenging for both parents and adolescents. No experience seemed to be universal, but they developed many unique and effective strategies in managing their fears. For parents, coping involved having current and future support from a variety of sources. One parent said that they cope with the stress, worry, and fear by relying on their “large circle of close and loving people” (P#001P). Another parent was more explicit when they mentioned “speaking to a counsellor, attending wellness clinics and doing a lot of research” (P#003P). Another parent mentioned they and their adolescent call the diabetes nurse educator regularly with their questions and it made them think about what supports adolescents with T1D may need and not have access to, especially as they become an adult and move to the adult healthcare system.

Similarly, the adolescents with T1D found several ways in which to find their way through their respective fears. Emotions including frustration, worry, and exhaustion were evident when adolescent participants were discussing the constancy of diabetes management.

“It’s manageable but it’s really frustrating” (P#003A). Another adolescent indicated their frustrations with T1D management by stating:

It can be extremely frustrating and annoying and like, it makes you a bit sad...what happened or why is all this stuff happening...it’s kind of...it’s weird because it’s not the worst chronic illness to have... because it’s extremely manageable but it’s...it’s really frustrating. It’s kind of like having a newborn baby but the baby never grows up. Like, it cries at you in the middle of the night to wake up and feed it and...like...just never matures, never grows up, never becomes independent (P#003A).

Many adolescent participants expressed a desire for more people to know about and understand T1D better. In effort to ensure they felt safe and healthy, one adolescent felt it necessary, but overwhelming, to provide teaching to those around them so they would know what to do if they saw the adolescent with T1D experiencing symptoms of hypoglycemia or hyperglycemia. “I feel like just having to explain in depth to everyone all the time, it is time consuming and a lot of work and repetitive...to constantly explain type one diabetes all the time...exhausting to constantly teach people” (P#006A).

Another adolescent stated:

The stress and pressure 24/7 isn’t really ever mentioned. I talk to my friends, family, write it out and trouble shoot it and let’s try this and see if it works. With high or low blood glucose I feel bad like I’m doing something wrong...I know I didn’t do anything wrong, but I feel like I did...even the question ‘why are you high?’ or ‘why did you go low?’ makes me feel like I’m doing something wrong even though I know I’m not. But I feel not well already if I’m high or low so that make me feel even worse...No one ever taught me or told me this might happen or what to try (P#006A).

Adolescents had some unique ways of coping with worries, frustrations, and fears. One adolescent mentioned they go on a “controlled binge of food as a way of coping...another thing I do is I throw away old handwritten records of blood sugars, so it feels like a reset and the beginning of something separate” (P#007A). Another said:

I mainly just forge ahead and then try to see later if there was something I could have done differently...if I’m high before bed and I have to give myself insulin and wait for it to work, I get extremely anxious if I just sit there and wait because I want to go to bed so I can get really anxious, so I just sit and play guitar or journal or do whatever for half an hour kind of thing to keep my mind off of it (P#006A).

Although fearing for the life of one’s adolescent can be compounded when the adolescent has a chronic illness like T1D, parents of adolescents with T1D have found ways to face this reality by seeing counselors, attending wellness clinics, and surrounding themselves with loving and supportive people. On the other hand, adolescents with T1D seem to face their fears of death in a far less structured way, trusting in the support of family and friends and developing more individualized strategies like playing guitar or doing a logbook reset. Regardless, having to face the fear of death at such a young age while one’s parents look on, almost helplessly, is not something anyone should have to experience without focused psychosocial assessments, guidance, and support for these unique experiences.

4.7 Discussion

Facing death is not a topic many people like to discuss, particularly with adolescents who have a chronic illness like T1D. It was surprising to notice in this reflexive thematic analysis that, although not being specifically asked about death, many participants shared their thoughts and feelings about death and openly discussed what they were doing to avoid death due to blood

glucose excursions. Both adolescent and parent participants freely discussed death as something they feared upon diagnosis, as they tried to avoid hypo- and hyperglycemia, and as a possibility due to long-term complications. This imminent threat of death seemed to cause the participants significant stress, which required a variety of coping mechanisms in order for the participants to function well day-to-day.

Globally, T1D is one of the most common long-term conditions in adolescents in the world (Simmons & Michel, 2015). The goal of optimal glycemic control of T1D is a significant source of stress for adolescents with T1D and their parents (Rechenberg et al., 2017) as deviations in glycemic control can cause immediate and long-term complications leading to death (Secrest et al., 2010). The specific experiences related to death have not been examined in relation to adolescents with T1D and their parents, although the literature clearly indicates T1D is associated with a substantially increased risk of premature death compared to the population without T1D (Lind et al., 2014; Morgan et al., 2015; Secrest et al., 2010; Tornese et al., 2015). There are very few studies investigating fear of death in relation to a new diagnosis of T1D.

The most prevalent fear related to adolescents with T1D discussed in the literature is a fear of hyperglycemia and hypoglycemia (Driscoll et al., 2018; Wherrett et al., 2018). Although the participants in this study did not specifically mention a fear of hypoglycemia or low blood sugar, they did express worry, anxiety, and stress related to low blood sugar and expressed a concern of dying as a result of low blood sugar, particularly when they are asleep. Much research has been done about the fear of hypoglycemia in adolescents with T1D and their parents, and how these fears impact A1C results (Shepard et al., 2014; Viaene et al., 2017). Worry, stress, and anxiety are associated with this fear of hypoglycemia and can result in avoidance behaviours such as carrying fast acting glucose, letting blood sugars run high, and more frequent blood sugar

monitoring (Viaene et al., 2017). Viaene et al. (2017) found that parental fear of hypoglycemia increased parental stress which is associated with increased A1C values in children with T1D. Our research did not specifically explore how the participants' fear of hypoglycemia affected T1D management behaviours, nor did we try to relate specific behaviours to the A1C. However, this fear of hypoglycemia seems so problematic and intense in some parents of adolescents with T1D that some parents "take over" the management of the adolescent's T1D at perhaps a developmentally inappropriate level, not allowing their adolescent to take on much if any of the management themselves. Shepard et al. (2014) found that interventions should be implemented sooner rather than later whenever extreme fear of hypoglycemia is exhibited. Some parents in the present study did mention different ways they were coping with the stress of T1D management, but not specifically for fear of hypoglycemia, while other parents did not mention ways they were coping with their stress at all. Future research could determine when would be the appropriate timing of interventions to minimize the fear of hypoglycemia and to explore any relationship this may have to perceptions related to death.

Many studies also indicate the acute negative and potentially life-threatening consequences of high and low blood sugars (Di Battista et al., 2009; Shepard et al., 2014). Some do investigate fears of glycemic excursions (Driscoll et al., 2016; Gonder-Frederick et al., 2006; Shepard et al., 2014). For example, Shepard et al. (2014) found that certain behaviours are manifested to accommodate the fear of hypoglycemia in children and adolescents with T1D and their parents, namely maintaining a high blood sugar especially at night and carrying fast acting sugar to avoid going low when away from the parent's side, as even continuous blood sugar monitors are not always reliable to recognize and alert them to a low occurring in the adolescent when either or both are asleep. Fear of hypoglycemia can be manifested in parents as constant

worry and feelings of helplessness (Shepard, 2014). Shepard et al. (2014) acknowledge that this fear can become problematic, and interventions should be implemented to address this fear. The results of the present study would support these conclusions to a lesser degree. It is possible that as some of these families are exhibiting fear of hypoglycemia, they would likely benefit from intervention as soon as possible (Shepard, 2014). Di Battista et al. (2009) investigated how fear of hypoglycemia and negative acute consequences of low blood sugar are related to social anxiety in adolescents with T1D, but again the possibility of death is not specifically indicated. They found the social anxieties of their participants were due to things like treating a low in front of their peers which then leads to non-adherence to a proper T1D management regime. Additional research should be conducted to determine the appropriate timing of interventions to minimize the fear of hypoglycemia.

Gonder-Frederick et al. (2006) do mention death as a possibility of hypoglycemia, but they do not investigate these thoughts or experiences to any extent. Specifically, Gonder-Frederick et al. (2006) found fear of hypoglycemia did lead to significant fear and could motivate some individuals to keep their blood sugar levels in the higher range to avoid hypoglycemia. They also found that the level of fear of hypoglycemia in adolescents with T1D coincided with frequency of severe low blood sugar episodes more than any other factor. They also found that the parental level of fear of hypoglycemia was mostly related to whether the adolescent had any fast-acting glucose with them in case of a low blood sugar episode and if their adolescent had experienced “unconsciousness due to hypoglycemia in the past” (Gonder-Frederick et al., 2006, p. 221). Which factors influence fear of hypoglycemia was not something that emerged from the data in the present study; however, it is interesting to note that those adolescents with T1D and their parents who talked about fear of hypoglycemia seemed to know a lot about hypoglycemia,

perhaps from experience, or from their physician, or perhaps other research they had done. Having information about hypoglycemia could have provided them some insight into the possibility of death due to hypoglycemia and subsequently perhaps discussing it with their child at some point.

Fear of hyperglycemia and potential subsequent DKA in adolescents with T1D was expressed by some of the participants of the present study. This fear of hyperglycemia seemed to mainly emerge during discussions associated with diagnosis of T1D. The fear of DKA was evident in some participants perhaps not necessarily because they were afraid of dying, but because the participants were afraid due to; how sick they were, how they feel when they have high blood sugar, worry that the DKA may require hospitalization, or the perceived judgment from others when they have high blood sugar or a high A1C. Further investigation is needed to ascertain why the fear exists, if death is part of the reason for the fears of hypoglycemia and hyperglycemia, and how these concepts are perceived by adolescents with T1D.

Fear and the blatant use of the words, *die*, *death*, and *dead* were mentioned regularly by the participants in this study, particularly in association with the diagnosis of T1D and surrounding frustrations and worries about T1D management. Investigations to see what coping strategies are used when faced with the diagnosis of T1D is warranted as knowledge of the stressors and how adolescents with T1D and their parents cope during that phase of illness is limited (Ersig et al., 2015). Are the adolescents and their families assessed for these fears and provided with education on the rarity of death occurring and linking their management education with avoidance of future morbidity and mortality? Some research suggests closed loop cutting edge technology provides alleviation of some worry and stress for some parents and adolescents with T1D (Barnard et al., 2014). Insulin pumps, flash glucose monitors, and continuous blood

sugar monitors are technological advancements in diabetes management that, when used properly, help to maintain target A1C levels well (Juvenile Diabetes Research Foundation (JDRF) Continuous Glucose Monitoring Study Group, 2009; Markowitz et al., 2013). Future research regarding access and use of this equipment is required as some studies have found lack of compliance due to costs of advanced technology devices (Rachmeil et al., 2015) and lack of understanding of the technology, lack of accessible support, and discomfort with wearing devices (Barnard et al., 2014; Landau et al., 2018). Additional research in this area could include a survey of a larger, more diverse sample to investigate if fear of death is a concern in adolescents with T1D and their parents and which interventions would prove most effective at reducing these anxieties.

4.8 Implications

This study has implications for nursing education, practice, and research. Nurses provide holistic care and require education about T1D diagnosis and management and what fears patients and their families may experience. To effectively support families if they encounter stress or fear when diagnosed with and managing T1D, nurses should actively listen, validate experiences, and include an assessment and discussion of the three themes of fear of death that were found in this research. Nurses should provide meaningful and easy to understand information about diabetes and its management. Nurses should show empathy and assist in creating an environment where families with T1D can feel safe and comfortable to communicate any fears they may be experiencing.

It is important to for nurses to assess adolescents with T1D and their parents for these fears and to provide them with support and tools to avoid glycemic excursions and to treat and cope with excursions when they do happen. Equally as important is increased health promotion

education in the community so there is enhanced awareness of the constancy of T1D management and what symptoms accompany glycemic excursions, so those with T1D can be supported properly and not inappropriately judged or mistreated when experiencing symptoms of high or low blood sugar.

Future research should be done to specifically focus on the presence of these fears in families living with T1D. A mixed method study should be conducted with a larger, more diverse population to validate the findings of this reflexive thematic analysis. Future research could also include the development of family-centered supportive care for families with T1D that may be experiencing fears.

4.9 Strengths and Limitations

This research provides important information on a topic where there is scant empirical literature. This new understanding of fear and death provides a foundation for additional investigation and may inform current healthcare practices. An additional strength of this study was the use of the constructivist grounded theory methodology in the original data collection which was rigorous and enabled an interpretive understanding of the experiences of adolescents with T1D and their parents from which this reflexive thematic analysis could be conducted.

There are some limitations to this study that need to be considered. This study has a homogeneous sample as it only involved adolescents with relatively well controlled diabetes living in western Canada who agreed to participate for the original study and not this thematic analysis. It is limited in ethnicity although both urban and rural participants are represented. Furthermore, as a secondary analysis the findings are bound to the data available and may carry some bias (Heaton, 2004; Heaton et al., 2019). However, it was clear that the fear of death was a

prevalent experience amongst the participants, thus, these findings allow for an initial examination of a topic worthwhile of future research.

4.10 Conclusion

The purpose of this research was to explore the experiences of fear and perceptions of facing death in adolescents with T1D and their parents based on a secondary analysis of qualitative interview data. Three themes were generated by this reflexive thematic analysis, 1) Reality of death, 2) Fearing the Highs and Lows, and 3) Finding a Way through Fears that describe the experiences of adolescents with T1D and their parents at diagnosis and throughout their management of T1D. There is a limited reporting of literature from an interpretivist viewpoint regarding the reality of facing death as an adolescent with T1D and how they and their parents face their fears of death when diagnosed with and managing T1D. The participants in this study indicated they see death as a consequence when they fail to optimally manage T1D. The themes generated by this research should be used to guide future investigation into the potential existence and prevalence of fear of death in adolescents with T1D. It seems important to ensure adolescents with T1D and their parents are assessed and are offered psychosocial support. Perhaps being offered counselling during diagnosis, during exacerbations, and at their regularly scheduled appointments to determine if any fears are present and if so, to ensure those fears are addressed.

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CHAPTER 5: DISCUSSION AND CONCLUSION

There are many potential reasons why adolescence is a period of challenges with T1D management, one of which is the negative impact on blood glucose with the withdrawal of parental support (Anderson et al., 2009; Borus and Laffel, 2010; Ingerski et al., 2010). I wanted to know more about what characteristics of the parent adolescent relationship may be helpful in enhancing optimal T1D management to hopefully assist with ensuring those helpful features can be identified and maintained throughout adolescence. This parent-adolescent relationship can be seen as interdependence; however, little is known about the nature and characteristics of interdependence as it applies to family management of T1D. Interdependence theory is used to analyze relationships and how they affect each individual within a group. There is limited research about interdependence theory to analyze the interactions between adolescents with T1D with their parents. Therefore, applying this theory of Managing the Unmanageable through Interdependence could have potential application to future research.

The overall purpose of this exploratory qualitative research was to understand the perceived nature of interdependence in the day-to-day management of T1D in adolescents with T1D and their parents. The specific objective of this research was to develop a substantive theory of interdependence that is grounded in the experiences and social context of adolescents with T1D and their parents. The research questions guiding this study included: How do adolescents with T1D and their parents define and describe interdependence?; what are the experiences of interdependence for adolescents diagnosed with T1D and their parents?; and, what are the processes of interdependence used by adolescents with T1D and their parents? In this Chapter, I will indicate why constructivist grounded theory was used for this qualitative research and I will discuss the findings from the preceding manuscripts and how they relate to the purpose and

research question(s), while also integrating the findings into the extant literature. Next, the overall strengths and limitations of this research along with future areas of research will be identified and a section on the concluding thoughts about my journey as a researcher and the impact of this work on myself will be presented.

5.1 Constructivist Grounded Theory

There is limited research about interdependence and the relationship between parents and their adolescents with T1D in the day-to-day management of T1D. No qualitative studies have been conducted to explore what interdependence means from the perspectives of adolescents with T1D and their parents. A constructivist grounded theory methodology was used in this study to allow for a theoretical understanding of the complex interactions between adolescents with T1D and their parents particularly with regards to the processes of interdependence as they navigate T1D management. Constructivist grounded theory enabled a better understanding of participant realities through thoughtful and interpretive discovery of the socially constructed meanings attributed by participants to their experiences (Charmaz, 2104).

In order to evaluate the current state of knowledge and refine the research question for this study, a literature review was conducted. The research questions were then refined to focus on the parent-adolescent interaction in T1D management and interdependence. Constructivist grounded theory was chosen as the most appropriate methodology to explore the social process. The substantive theory that emerged from the data from 32 open-ended interviews, is grounded in the experiences of the participants, which were interpreted and then described by myself, the researcher. This substantive theory permits unique understanding of the experiences of interdependence of adolescent with T1D and their parents. While many participants saw interdependence as teamwork, the nature of this teamwork changed over time as the adolescent

aged. The substantive theory of interdependence developed in this research helps to facilitate optimal T1D management during adolescence, showing the importance of each subprocess. No subprocess should be minimized or ignored because all of them seem to help to optimize glycemic control. This model provides a visual tool to help the healthcare team operationalize the grounded theory in their assessment and education of adolescents and their families, supporting management of T1D.

The adolescent participants in this study indicated they wanted support but were not aware they could or should ask for support. The participants indicated self-management was the goal from the first day of their diagnosis and seeking support from parents and others seemed to be linked with some failure on their part. Diagnosis of T1D must be an overwhelming time, so to be able to utilize a visual model that shows how many facets are involved in managing T1D care to adolescents with T1D and their families, could be a way to ensure support is encouraged and validated. The next stages of this research are necessary to determine the effects of utilization of the model on glycemic control.

5.2 Manuscript Findings in Relation to the Goal of this Dissertation

5.2.1 Manuscript 1: Type 1 Diabetes Management Responsibilities between Adolescents with T1D and their Parents: An Integrative Review

Currently, adolescents with T1D are encouraged to direct their T1D care towards self-management, yet many adolescents with T1D seem to be struggling with adequate glycemic control (Wherrett et al., 2018). It may be possible that adolescents with T1D are pressured to be independent too soon and that a different approach to T1D management may be warranted. Perhaps applying interdependence to management of T1D with adolescents and their parents may provide a useful solution. Before conducting a qualitative study exploring interdependence,

a survey of the current literature was necessary to assess the current state of knowledge, identify any gaps in the literature and determine the role of interdependence in the management of T1D of adolescents with their parents. Initial investigation determined that the term interdependence has been rarely used in the management of T1D in adolescents; therefore, the search criteria was expanded to include the sharing of responsibility of T1D management among the adolescent and their parents (Anderson et al., 1997; Hanna et al., 2012; Trudeau et al., 2019).

Following completion of the integrative review, 11 studies were found that fit the inclusion criteria and a thematic analysis was conducted, resulting in three themes: Effectiveness of Parental Involvement and T1D Management; Shared Responsibility and T1D Task Management; and Gaining Independence in T1D Management. The analysis also revealed that interdependence was not well-articulated in these studies but was often described as shared responsibility of tasks involved in management of T1D. The quantity of sharing of responsibility was evident, yet the quality of this sharing was not often identified. However, it was clear that adolescents and parents need to be working together to manage T1D (Farthing et al., 2022b).

These findings made it clear that parents play an important role in supporting their adolescent with management of T1D and it appears interdependence is a concept not used in the research literature and often referenced through the term shared responsibility that requires careful consideration in planning effective health care. This review also revealed that more research into the nature of shared responsibility and interdependence was needed to determine exactly how glycemic control could be improved by parents remaining involved in the T1D management of their adolescent.

The next step of this dissertation was to determine what the current understandings of interdependence were in a population of adolescents with T1D and their parents using the themes

from the literature review to inform the research process (modify the purpose and research questions and direct the development of the interview guide). The qualitative method of constructivist grounded theory was chosen for this investigation as previous research is lacking in this area. This approach facilitated a unique perspective grounded in the experiences of each participant and the development of a substantive grounded theory.

5.2.2 Manuscript 2: Managing the Unmanageable through Interdependence in Adolescents Living with Type 1 Diabetes and their Parents: A Constructivist Grounded Theory

The substantive grounded theory that emerged from the analysis of the participants' experiences described the context within which parents' and adolescents' experience the main concern. Additionally, the grounded theory described how the participants resolve their main concern via the basic social process and four related subprocesses. To the best of my knowledge, this was the first study to investigate interdependence through a qualitative lens in the context of adolescents with T1D and their parents. The substantive theory that emerged from this data, *Managing the Unmanageable through Interdependence*, described the parents' and adolescents' main concern of Maintaining Optimal Glycemic Control within the context of the ever-changing Nature of the Illness. This study found four related subprocesses that adolescents with T1D and their parents use to resolve their main concern within this context. These subprocesses include Completing T1D Tasks (the daily tasks required to reach the goal of optimal glycemic control), Attaining Support (assistance with T1D tasks by people outside the adolescent-parent relationship), Reconciling Reality (coping with the initial stress of diagnosis and daily pressures of T1D management) and Balancing Independence (the conflict between promoting independent management and providing/needing assistance) (Farthing et al., in press).

The reflexive relationship of the researcher and participants facilitated a rich in-depth examination of the experiences of the participants (Charmaz, 2014). As I am a nurse, a nurse educator, a researcher, and a mother of a son with T1D, rapport was easily established during the interviews as it was clear to the participants, I was able to understand their vernacular and some of their experiences. In my reflexive journaling after the interviews, it was evident the participants were delving into topics I had never thought of or experienced and I think, in part, it was because of their comfort level with talking to me. I was easily able to empathize and ask relevant questions based off of what they were disclosing and discussing in the interview. I had a hard time holding back tears when the participants got emotional but rich data was collected as a result of our interviews and discussions. Given the emotional content of some of the interviews, reflexive journaling was consistently used to ensure an unbiased approach to data collection and analysis.

This study explored the experiences of both the adolescent and their parents and found that participants in this study perceive interdependence as more than a sharing of responsibilities of T1D management among adolescents and their parents. Most of these participants experience interdependence with their parents but also experience support at a different level with those outside of the home who are willing to learn about T1D and help provide assistance to maintain glycemic control.

While current practice in the health care of adolescents with T1D encourages independence and self-reliance, findings from this study suggest that adolescents and their parents benefit from an interdependent relationship that is dynamic and varies by situation and by age and time since T1D diagnosis. By understanding interdependence, nurses can individualize T1D care and family support, which could potentially lead to better long-term

disease management. Future research is needed to determine both the role of health professionals and others in promoting interdependence, and what is the impact of interdependence on diabetes management overall. Also, research investigating the facilitation of this process from diagnosis of T1D through transition to adulthood is necessary.

5.2.3 Manuscript 3: Perceptions Relation to Death in Adolescents with T1D and their Parents during the Management of Type 1 Diabetes: A Thematic Analysis

T1D is a long-term condition and immediate and long-term complications can lead to additional morbidity and even death. It seemed evident as the data were being analyzed that some participants were thinking about death, which seems unusual particularly given their own, or their adolescent's, age. Thoughts of invincibility are more typical during adolescence, so they are inclined to take more risks and they often have a wider social network, which often includes more time with and influence from their peers, leading to risk taking behaviour and potential disregard of death or dying (Santrock, 2021).

Yet, for the adolescents with T1D and their parents in this study something was different. Because of this, I decided to do a reflexive thematic analysis of the data collected from the primary grounded theory research, in order to seek a deeper understanding of the participants' perceptions of fear, death, and dying. Therefore, the purpose of this study was to explore adolescents' and their parents' perceptions of fears related to the possibility of death that may have been hidden in the data collected for the primary research meant to address interdependence.

After coding the data, using Braun and Clarke's systematic analytical method (2006, 2019), experiences associated with fear, anxiety, stress, coping, death and dying, determined three themes. The themes that were developed included: 1) Reality of Death, 2) Fearing the

Highs and Lows, and 3) Finding a Way through Fears (Farthing et al., 2022a). No research was found that directly investigated reality and perceptions related to death in adolescents with T1D and their parents. The fear of hypoglycemia was frequently mentioned in the literature (Barnard et al., 2014; Borus & Laffel, 2015; Ersig et al., 2015; Shepard et al., 2014); however, the literature is scant on how adolescents with T1D and their parents cope with other fears they may have. As this was a secondary analysis, we were not able to explore in more detail the participants' fear of death or how they coped with those fears.

The purpose of this dissertation research was to understand the experiences and related processes of interdependence in adolescents with T1D and their parents. Manuscript 3 contributes to this purpose in that interdependence plays a role in maintaining glycemic control and may potentially play a role in coping with the reality of death that both the adolescent and the parents face.

The concepts and themes generated in manuscript 3, particularly how the participants find a way through their fears, add to the findings of manuscript 2. Interdependence could be considered as a way to help adolescents with T1D and their parents, discuss and cope with the possibility of death that accompanies a T1D diagnosis and management of T1D for the rest of their lives. Additionally, some of the participants alluded to the absence of any prescribed methods of coping with the reality of death beginning with diagnosis, preventing long term complications and even with the dangers surrounding glycemic excursions. Interdependence may help to manage the fear of death that adolescents with T1D and their parents may face. Manuscript 3 also extends the understanding of the participants' experiences more broadly beyond interdependence and highlights the need for focused intervention, given the persistent and serious nature of these perceptions.

The present study provides unique insights that help to increase the understanding of the adolescents with T1D and their parents' experiences while managing T1D. Future research to investigate the reality of death that adolescents with T1D and their parents face, is needed. The strengths and limitations of this dissertation research study will be addressed in the next section.

5.3 Strengths and Limitations

The first strength of the research found within this dissertation is the combination of the work contained in each of the three manuscripts which ensured a strong presentation of information. Another strength is the rigorous integrative review that synthesized the existing literature and identified gaps in existing knowledge and highlighted areas of future research. A third strength is the use of a constructivist grounded theory approach which included my personal and professional background as a researcher in the research process. As a pediatric nurse with almost 30 years of experience, as well as being the mother of a son with T1D for over 25 years, I was able to establish a quick rapport and level of understanding of T1D when conducting the interviews. The substantive grounded theory that emerged from the research is unique, enhances knowledge, and has implications for nursing practice, education, and research. This research also provides information on topic areas that are scant in the empirical literature.

There were some limitations to this research. The literature review did not examine the theoretical literature and only included studies published in English. A broader review could examine the differences between countries and any cultural influences. Causality could not be established as many of the quantitative studies were cross-sectional. The studies that were found were all from the United States, had smaller sample sizes, and varied adolescent age ranges, which limits the comparisons of findings. The participants in this dissertation research were limited to a small sample size from one western Canadian province. However, both rural and

urban families participated. The sample of participants was fairly homogenous; Caucasian with both parents participating in childcare. However, most parent participants were mothers and not all adolescents had a parent participating. Most interviews were conducted by videoconference although a few interviews were conducted by telephone. In the latter form of interview, about non-verbal communication could not be observed, but vocal expression was available. Also, the substantive grounded theory is an interpretive rendering of the data and my subjectivity as the researcher needs to be recognized as there may be other understandings of the data. Nonetheless, these findings do offer new understandings, enrich knowledge, and have theoretical reach.

5.4 Implications for Practice, Education, and Research

There are many implications for nursing practice, education, and research that have been established from this study. These findings help to support a better understanding of family management of T1D in adolescence. It is important to consider integrating the concept of interdependence into diabetes management guidelines. The model of interdependence could help provide a visual illustration for practitioners and families of the complexities of T1D management and how difficult it can be to always attain optimal glycemic control. For example, if parents are not willing to be involved in T1D management, the platform of Interdependence is totally tilted, and everything falls to the adolescent. Doing so, throws T1D management out of balance and it is clear to see how optimal glycemic control (red circle) is impacted, and as a result, near impossible to attain. The reverse is also true, and easy to visualize, if the adolescent decides they are not willing to participate in their own T1D management. Another example might involve Reconciling Reality, if the parents and the adolescents do not have strategies to cope with the stresses they may encounter, the removal of the purple triangle also disrupts the

balance, most immediately of T1D tasks, which then again impacts the attainment of optimal glycemic control.

The model could be used by nurses working in the community and in acute care to reassure (e.g., active listening, validating experiences, offer supportive care), to assist with assessments (assess family support, interdependence, community support, adolescent's level of independence with T1D management, and how T1D tasks are distributed within the family), and to help provide holistic individualized care for families managing T1D. While self-management is the current focus of T1D management in adolescence, the findings indicate that an interdependent approach should be considered as it may be more effective during adolescence. For example, it should be made clear, during the teaching of family T1D management, that requiring or requesting assistance for diabetes management is a necessary component of having a chronic illness and should never indicate the family is being judged, or that they are ineffective, or unable to manage T1D. Nurses should learn how to communicate effectively to families about T1D management to ensure encouraging interactions without judgments or criticisms. Nurses need to ensure that families know they are not alone once they have a T1D diagnosis and providing information on supports available in the clinic, community, and current and new management technologies available when families feel they cannot manage on their own. At subsequent clinic appointments, the nurse can help train the family caregivers on how to support the adolescent with T1D with proper communication such as by encouraging and offering assistance instead of questioning or criticizing how the adolescent is performing the necessary tasks.

The requirement for future research is evident due to the lack of research about interdependence from the perspective of adolescents and their parents, the limitations of this

research, and the gaps identified herein. The findings indicate the importance and effectiveness of an interdependent sharing of responsibility of T1D management that is mediated by age.

Interdependence is a multifaceted concept; thus, more research is required to examine the dynamics of parental involvement in care and the nature of interdependence to determine how best to work towards an interdependent approach to T1D management for adolescents.

Quantitative research should be conducted to test the validity of the model of interdependence and its components and how they impact glycemic control, with a larger, more diverse sample.

More qualitative studies are also necessary to explore what interdependence means to in the context of the family and how effective or ineffective this approach may be.

Future research should expand the qualitative understanding of the experiences of interdependence by including a larger more culturally diverse sample, participants in other healthcare settings including emergency rooms and hospitals, older age groups, and more diverse households. Also, investigation into the importance of interdependence and the subprocesses of interdependence using quantitative or mixed methods approaches would help to validate the model and quantify any effect on glycemic control during adolescence and into adulthood.

A finding from the integrative review was a deficiency in the tools used to measure shared responsibility and interdependence. The development of a tool or questionnaire to measure interdependence, similar to the DFRQ but expanded to include all four subprocesses, to provide a more accurate, enhanced, and detailed way to assess the various facets of interdependent sharing of T1D management.

Components of the substantive grounded theory could be confirmed or revised through a Delphi study and subsequently used as a framework for a checklist or mobile application. With this additional validation, the checklist/application could be used as part of day-to-day T1D

management starting at diagnosis and at all future appointments to ensure all components of the model are being addressed.

An important finding that also requires more research is the extent of the impact of the concept of death in this population. A study dedicated to clarifying what death means to children and adolescents diagnosed with T1D and their parents is warranted. Exploration of how and why they have worry and fear about the concept of death would be helpful so they can be better directed, educated, and supported. When interviewing or working with families, it would be important to provide a therapeutic environment that minimizes any feelings of shame or blame so that families feel comfortable to discuss whatever feelings they may or may not have regarding death. Having these types of open discussions could contribute to the development of more tailored intervention strategies, the correction of misinformation or misunderstanding, and an opportunity for the family to be heard. Enhanced support of adolescents with T1D may result in improved health, reduced complications, and decreased stress associated with T1D.

5.5 Concluding Thoughts

Through the development of three manuscripts that included an integrative literature review, a constructivist grounded theory study, and a reflexive thematic analysis, I was able to examine the experiences and related processes of interdependence in adolescents with T1D and their parents.

During the research process, I have gained new knowledge through the completion of an integrative literature review and by using constructive grounded theory as the primary research methodology, neither of which I have endeavored to conduct before. Constructivist grounded theory as the methodology allowed my professional and personal background and expertise to be utilized in a unique way. As a mother of a son with T1D since he was five years old, I was at

times able to compare my diabetes care experiences with those of the parent participants. Like the participants, I know our family and I would have valued more support from people that understood T1D throughout our son's life, even now. We were, and most importantly, he was left to figure things out on his own as an adolescent and as a young adult moving into the adult healthcare system.

What changed in me through the course of this study, is mainly my confidence in the process of qualitative research. My background is quantitative research and therefore it was challenging to delve into an area very out of my past research experiences. I was so encouraged to discover that qualitative research, particularly constructivist grounded theory, does involve a logical process that brings confidence to the findings and is a springboard for future qualitative, mixed methods, and quantitative research.

I am grateful to the participants in this study during this research process for their time and willingness to share their experiences with me. My hope is that positive changes can be affected for all those diagnosed and living with T1D as a result of their participation. The adolescents with T1D and their parents that I was privileged to work with are true heroes and deserve all the help and support that we can garner for them to ensure they live happy, healthy, long lives in spite of this challenging long-term condition.

Support and interdependence with their parents could positively impact glycemic control during adolescence. As numbers of adolescents with T1D continue to rise, more research is urgently needed to ensure those with T1D and their families are well supported particularly through adolescence. The research questions I posed for this dissertation have been answered but in doing so, even more questions have been raised. I look forward to continuing research in this area and inspiring others to do so, as well.

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Appendix A

Ethics Approval Certificate



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB) 31-Jul-2019

Certificate of Approval

Application ID: 925

Principal Investigator: Jill Bally

Department: College of Nursing

Locations Where Research
Activities are Conducted: Saskatoon, SK Canada, Canada

Student(s): Pamela Farthing

Funder(s):

Sponsor:

Title: Interdependence in Adolescents with Type One Diabetes and their Parents

Approved On: 31/07/2019

Expiry Date: 30/07/2020

Approval Of: Behavioural Research Ethics Application

Demographic questionnaires (adolescents, parents)

Interview and discussion guides (adolescents, parents)

Consent forms and cover letter (adolescents, parents, assent, parental consent)

Confidentiality agreement

Recruitment email

Recruitment poster

Acknowledgment Of:

Review Type: Delegated Review

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2014). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this project, and for ensuring that the authorized project is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the project remains open, and upon project completion. Please refer to the following website for further instructions: <https://vpresearch.usask.ca/researchers/forms.php>.

*Digitally Approved by Stephanie Martin, Vice Chair
Behavioural Research Ethics Board
University of Saskatchewan*

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Appendix B

Participant Recruitment Email

Are you a teen with type 1 diabetes?

Are you the parent of a teen with type 1 diabetes?

We Need your Expertise!

Are you a teen age 10-18 who has been diagnosed with type 1 diabetes (T1D) for at least one year?

OR

Are you the parent of a teen who has had T1D for at least one year and you have been actively involved in their diabetes care since they were diagnosed?

AND

Are you both willing to be interviewed separately, in person or remotely (by telephone or videoconference) about your experiences living with T1D?

There will be two to three interviews for each of you which will take approximately 30-90 minutes apiece. Your participation will be kept confidential, and you may enter a draw for a \$100.00 gift card of your choice at the end of the interviews as our thanks to you for your time and input.

If you are interested in participating in this research, or have any questions please contact:

Pamela Farthing RN, BA, MSc, PhD(c)

pamela.farthing@usask.ca

This research is being conducted by a PhD candidate in the College of Nursing at the University of Saskatchewan. This study was approved by the University of Saskatchewan ethics on July 31, 2019 (Beh-REB #925) and has operational approval to conduct research from the Saskatchewan Health Authority.



Appendix C

Participant Recruitment Poster

Are you a teen with type 1 diabetes? Are you the parent of a teen with type 1 diabetes? We need your expertise!

We are inviting teens age 10-18 with type 1 diabetes (T1D) for at least one year and their parents/guardians to be interviewed

Who can be in the study:

- Teen age 10-18 living with T1D for at least one year
- Have a parent parent/guardian involved in diabetes care since diagnosis
- Both parent and teen willing to be interviewed separately in person or remotely (by telephone or videoconference) for 30-90 minutes about your experiences living with T1D



****Complete an interview and you can enter a draw for a gift card****

If you're interested in this research and/or have questions, please contact:

Pamela Farthing PhD candidate
College of Nursing
pamela.farthing@usask.ca



UNIVERSITY OF SASKATCHEWAN
College of Nursing
NURSING.USASK.CA

This project received U of S ethics approval on July 31, 2019 (Beh-REB#925) and has operational approval from SHA

Appendix D

Participant Recruitment Bucksheet

We need your expertise!

- Are you a teen age 10-18 living with T1D for at least one year with a parent/guardian involved in your diabetes care since diagnosis?
- Are you willing to be interviewed in person or remotely (by telephone or videoconference) for 30-90 minutes about your experiences living with T1D?

If you are interested in this research and/or have questions, please contact:

Pamela Farthing PhD Candidate
pamela.farthing@usask.ca
(306)659-4199

U of S Beh-REB approval ID #925



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Appendix E

Cover Letter to Accompany Consent Forms



College of Nursing
104 Clinic Place, Saskatoon, Saskatchewan S7N 2Z4
Telephone: (306) 966-6221 Facsimile: (306) 966-6621

A Study of Caring for Adolescents with Type 1 Diabetes

Dear <Name of Participants>;

Thank you for your interest in the study of caring for Adolescents with type 1 diabetes. Currently, there is very little research about how families and persons with diabetes work together to care for children with diabetes. You and your adolescent are being invited to participate in this study because your teen has been living with Type 1 diabetes for at least a year and as a parent or guardian, you have also been involved with your adolescent's diabetes care from the beginning. I believe that your personal experiences will help build a better understanding of the issues that families encounter with diabetes.

Please note that your participation in this study is voluntary. I have enclosed a consent form for your review and an assent form for your teen <Name> to review. If you have any questions about what you or your teen have read, you can contact me at (306)659-4199 (work). If you agree to be part of this study, please sign and date the consent form and have your child read the assent form and sign and date that. You can scan and return the consent and assent forms by email or mail them in the addressed pre-paid envelope.

I look forward to learning about your experiences. Once I have received the consents to participate in the study, I will contact you to arrange a time to begin the interviews.

Sincerely,

Pamela Farthing RN, MSc, PhD(c)
Doctoral Candidate
College of Nursing
University of Saskatchewan
(306)659-4199
pamela.farthing@usask.ca

This study was approved by the University of Saskatchewan ethics on July 31, 2019 (Beh-REB #925) and [insert once obtained] has operational approval to conduct research from the Saskatchewan Health Authority.

Appendix F

Consent Form for Parent/Guardian of Adolescent

Caring for Adolescents with Type 1 Diabetes



Project Title:

Caring for Adolescents with Type 1 Diabetes

Researcher:

Pamela Farthing, RN BA MSc PhD(c) pamela.farthing@usask.ca (306)659-4199

PhD Co-supervisors:

Dr. Jill Bally jill.bally@usask.ca

Dr. Donna Rennie donna.rennie@usask.ca

Purpose of the Research:

The purpose of this project is to learn about the experiences and thoughts about managing diabetes with your teen with type 1 diabetes (T1D) and any support you may receive to do so.

You and your adolescent are being invited to participate in this study because your teen has been living with Type 1 diabetes for at least a year and as a parent or guardian, you have also been involved with your adolescent's diabetes care from the beginning. The results of the study will help adolescents with T1D, families and healthcare practitioners better manage T1D.

Procedures:

You are a parent of an adolescent with T1D. Any contact information provided in the interview, will only be accessed by Pamela Farthing. You will be asked to participate in a series of 2-3

interviews. The interviews should take approximately 30-90 minutes each to complete. Your contact information will be destroyed once the interviews are complete.

If you agree to be part of this study, the interview can be done at the Pediatric Diabetes Clinic you attend, by telephone or by videoconference (on a computer). You will be asked to answer questions about yourself (gender, age, etc.) these answered will not be audio recorded. Then you will be asked questions about how you and your teen manage T1D and any support you receive to do so. If it is OK with you, what we will talk about will be audio taped. The recording device can be turned off by request at any point during the interview without giving a reason. This interview will take approximately 30-90 minutes. I would like to talk with you again at a time that is best for you, about two weeks after our first meeting. I will use this time to answer any questions, to verify my understanding of our first discussion, and to address any questions that may arise. The second interview should take approximately 30-45 minutes. If a third interview is required to verify understanding it would take approximately 30 minutes.

Potential Risks:

- The interview involves sharing personal experiences of living with and managing T1D you may choose which questions to answer. If you get tired, uncomfortable, or upset you can choose to take a break or end the interview at any time.

Potential Benefits:

- Taking part in this study may not benefit you or your teen directly, however, the information that is provided may be of help to others. This information can be used by healthcare professionals to provide improved and more effective health care for families in similar situations.

Confidentiality:

- The interview will be digitally recorded. The interview will be conducted by the researcher, she and a transcriptionist will have access to this original data.
- No identifying information, other than your voice, will be available on the recording. The person transcribing the audio recording may or may not be able to recognize your voice, however they will be familiar with confidentiality and have signed a confidentiality agreement.

- Any identifying information, either of yourself or names of others and institutions, will not be used on the final transcripts. The researcher will have access to the transcripts to conduct analysis.
- Interview data will be presented and shared in aggregate form.
- **Storage of Data:** Data will be stored on a password protected computer and a password protected external storage device (i.e., external hard drive) in a locked drawer (both in Dr. Jill Bally's office at the College of Nursing at the University of Saskatchewan). Copies of the consent form will be stored separately from the data also in a locked drawer in Dr. Bally's office. The forms and data will be kept for a minimum of 5 years after the study is complete and will then be destroyed by the researcher.

Right to Withdraw:

If you decide to participate or not on this study it will not affect your access to services, such as health care. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort. However, once we mix your information with that of the other people in the study, we will no longer be able to take out your information. The deadline to ensure withdrawal of all of your data will be two weeks after the final interview is complete.

Follow up:

If you have any questions or would like to obtain results from the study, which should be available by July 2021, please contact Pamela Farthing at (306) 659-4199 or by email pamela.farthing@usask.ca

Questions or concerns:

- You may contact any of the researchers listed at the beginning of the consent form.
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board as being ethically sound on **(July 31, 2019) (Beh-REB ID #925)**. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Consent to Participate:

Your signature below indicates that you have read and understand the description provided; you have had an opportunity to ask questions and your questions have been answered. You consent for your teen to participate in the research project.

A copy of this consent will be given to you via Adobe sign email, and a copy will be available to the researcher.

Name of Participant _____
Signature _____
Date

Name of Researcher _____
Signature _____
Date

Appendix G

Consent Form for Parent/Guardian on behalf of an Adolescent under 18

Caring for Adolescents with Type 1 Diabetes



Project Title:

Caring for Adolescents with Type 1 Diabetes

Researcher:

Pamela Farthing, RN BA MSc PhD(c) pamela.farthing@usask.ca (306)659-4199

PhD Co-supervisors:

Dr. Jill Bally jill.bally@usask.ca

Dr. Donna Rennie donna.rennie@usask.ca

Purpose of the Research:

The purpose of this project is to learn about your teen's experiences and thoughts about managing diabetes their type 1 diabetes (T1D) and any support they may receive to do so. You and your adolescent are being invited to participate in this study because your teen has been living with Type 1 diabetes for at least a year and as a parent or guardian, you have also been involved with your adolescent's diabetes care from the beginning. The results of the study will help adolescents with T1D, families and healthcare practitioners better manage T1D.

Procedures:

You are a parent of an adolescent with T1D. Any contact information provided in the interview, will only be accessed by the Pamela Farthing. Your teen will be asked to participate in a series of

2-3 interviews. The interviews should take approximately 30-90 minutes each to complete. Your contact information will be destroyed once the interviews are complete.

If you agree for your teen to be part of this study, the interview will be done by telephone or by Zoom videoconference (on a computer). At the beginning of the interview, your teen will be asked to answer some questions about themselves (gender, age, etc.). These initial questions will not be audio recorded. Then they will be asked questions about how you and your teen manage T1D and any support you or your teen receive to do so. This part of the interview will be audio taped. The recording device can be turned off by request of your teen at any point during the interview. No reason is required to stop the recording. This interview will take approximately 30-90 minutes. The researcher would like to talk with your teen at a time that is best for you and your teen, about two weeks after our first meeting. I will use this time to verify my understanding of our first interview, and to address any questions that may arise. The second interview should take approximately 30-45 minutes. If a third interview is required to verify understanding it would take approximately 30 minutes.

Potential Risks:

- The interview involves sharing personal experiences of living with and managing T1D. Your teen can choose which questions to answer. If they get tired, uncomfortable, or upset they can choose to take a break or end the interview at any time.

Potential Benefits:

- Taking part in this study may not benefit you or your teen directly, however, the information that is provided may be of help to others. This information can be used by healthcare professionals to provide improved and more effective health care for families in similar situations.

Confidentiality:

- The interview will be digitally recorded. The interview will be conducted by the researcher, she and a transcriptionist will have access to this original data.
- No identifying information, other than your teen's voice, will be available on the recording. The person transcribing the audio recording may or may not be able to

recognize your teen's voice, however they will be familiar with confidentiality and have signed a confidentiality agreement.

- Any identifying information, either of yourself or names of others and institutions, will be de-identified on the final transcripts. The researcher will have access to the transcripts to conduct analysis.
- Interview data will be presented and disseminated in aggregate form.
- **Storage of Data:** Data will be stored on a password protected computer and a password protected external storage device (i.e., external hard drive) in a locked drawer, both of which are in Dr. Jill Bally's office at the College of Nursing at the University of Saskatchewan. Copies of the consent form will be stored separately from the data also in a locked drawer in Dr. Bally's office. The forms and data will be kept for a minimum of 5 years after the study is complete and will then be destroyed by the researcher.

Right to Withdraw:

Your teen's participation is voluntary, and they need only answer those questions that they are comfortable with. Participation will not affect your or your teen's access to services, such as health care. Your adolescent may withdraw from the research project for any reason, at any time, without explanation or penalty of any sort. However, once we mix their information with that of the other teens in the study, we will no longer be able to take out their information. The deadline to ensure withdrawal of all of your teen's data will be two weeks after their final interview is complete.

Follow up:

If you want to know the results of this study or have any questions about the study, which will be available by July 2021, please contact Pamela Farthing (306) 659-4199 or by email at pamela.farthing@usask.ca

Questions or concerns:

- You may contact any of the researchers listed at the beginning of the consent form.
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board as being ethically sound on **(July 31, 2019) (Beh-REB ID #925)**. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Consent to Participate:

Your signature below indicates that you have read and understand the description provided; you have had an opportunity to ask questions and your questions have been answered. You consent for your teen to participate in the research project.

A copy of this consent will be given to you via Adobe sign email, and a copy will be available to the researcher.

_____	_____	_____
<i>Name of Teen Participant's</i>	<i>Signature</i>	<i>Date</i>
<i>Parent/Guardian</i>		

_____	_____	_____
<i>Name of Researcher</i>	<i>Signature</i>	<i>Date</i>

Appendix H

Caring for Adolescents with Type 1 Diabetes Assent Form



Title of the Study:

Caring for Adolescents with Type 1 Diabetes

Researcher:

Pamela Farthing, RN BA MSc PhD(c) pamela.farthing@usask.ca (306)659-4199 (work)

PhD Co-supervisors:

Dr. Jill Bally jill.bally@usask.ca

Dr. Donna Rennie donna.rennie@usask.ca

What is the study about? We are doing a research study to understand you and your parent's thoughts and experiences about managing your diabetes. Taking part in this study may not help you directly, but we think what we find with your help might be useful for others your age, their families, nurses and doctors.

What will I have to do? If you decide that you want to be part of this study, Pamela Farthing, a researcher, will contact you to set up a time to meet with you. She will first have you complete a questionnaire about your diabetes followed by an interview about your thoughts and experiences living with diabetes. The interview will take place at a time that suits you. The first interview will be longer and may last up to one hour and a half. If needed and with your okay, we may interview you one or two more times to talk more about some of your answers. The second and third interviews will be shorter, lasting around 30 minutes.

What will you do with what I tell you? Pamela Farthing will do the interviews. She will need to record the interviews. You can ask for the recording to be stopped at any time without giving a reason. Any recordings and paper information will be kept in a locked file drawer. The recordings are needed to look at the information from the interview in more detail. As part of this study the researchers will protect your name and will not tell others that you were part of the study. Only the main researcher, P. Farthing, who will interview you, will know who you are. All of the interviews will be used together as part of the findings. Your name will not be used in any of the reports of the findings. As well, during the interview you only need to answer those questions that you want to answer. We are discussing the study with your parents and you can talk to them about it as well.

Where will the interviews be held? If you agree to be part of this study, the interview can be done at the Pediatric Diabetes Clinic you attend, by telephone or by videoconference (on a computer).

Will this study cause me any harm? The interview should not cause you any harm, but some questions may cause you to think a lot.

What if I have questions about the study as I participate? The researcher will ask at the start of each interview if you have any questions. You can ask questions at any time during the interview if you do not understand any part of the study.

How does this study benefit me? Taking part in this study may not help you but by being in this study you could help to improve nursing research with families of adolescents with diabetes. As we said earlier, the information that you provide may be of help to others. The findings from the study can be used by nurses and doctors to provide better health care for families in similar situations.

Right to Withdraw:

What will happen if I don't want to be part of this study? You do not have to be part of this study. If you decide now or in the future, that you do not want to be a part of the study, nobody will be angry or upset and it would not affect your relationship with your doctor or your diabetes clinic. However, once we mix your information with that of the other people in the study, we will no longer be able to take out your information. The deadline to ensure withdrawal of all of your data will be two weeks after your final interview is complete.

If you want to know the results of this study or have any questions about the study, which will be available by July 2021, please contact Pamela Farthing (306) 659-4199 (work) or by email at pamela.farthing@usask.ca

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board as being ethically sound on **(July 31, 2019) (Beh-REB ID #925)**. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975

Your completed assent form and your parents' consent form will be stored separately from the research data in locked drawers and/or a password-protected computer in Dr. Jill Bally's office at the College of Nursing, for at least five years. Only the research team will be able to look at this information.

We will give you a copy of what you have signed so you can look at it again if you need to. The researcher will also have a copy.

I, _____ (Print or write your name) would like to be in this research study.

_____ (Date of assent)

_____ (Name of person who obtained assent)

_____ (Signature of person who obtained assent)

_____ (Date)

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board as being ethically sound on **(July 31, 2019) (Beh-REB ID #925)**. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Appendix I

Consent Form Adolescent Age 18

Caring for Adolescents with Type 1 Diabetes



Project Title:

Caring for Adolescents with Type 1 Diabetes

Researcher:

Pamela Farthing, RN BA MSc PhD(c) pamela.farthing@usask.ca (306)659-4199

PhD Co-supervisors:

Dr. Jill Bally jill.bally@usask.ca

Dr. Donna Rennie donna.rennie@usask.ca

Purpose of the Research:

We are doing a research study to understand your thoughts and experiences about managing your diabetes. Taking part in this study may not help you directly, but we think what we find with your help might be useful for others your age, their families, nurses and doctors.

Procedures:

If you decide that you want to be part of this study, Pamela Farthing, a researcher, will contact you to set up a time to meet with you. We will first have you complete a questionnaire about your diabetes followed by an interview about your thoughts and experiences living with diabetes. The interviews will take place at a time that suits you. The first interview will be longer and may last up to one hour and a half. If needed and with your okay, we may interview you one or two

more times to talk more about some of your answers. The second and third interviews will be shorter, lasting around 30 minutes.

Pamela Farthing will do the interviews. She will need to record the interviews. You can ask for the recording to be stopped at any time without giving a reason. Any recordings and paper information will be kept in a locked file drawer. The recordings are needed to look at the information from the interview in more detail. As part of this study the researchers will protect your name and will not tell others that you were part of the study. Only the main researcher, P. Farthing, who will interview you, will know who you are. All of the interviews will be used together as part of the findings. Your name will not be used in any of the reports of the findings. As well, during the interview you only need to answer those questions that you want to answer. We are discussing the study with your parents and you can talk to them about it as well.

If you agree to be part of this study, the interview can be done at the Pediatric Diabetes Clinic you attend, by telephone or by videoconference (on a computer).

The researcher will ask at the start of each interview if you have any questions. You can ask questions at any time during the interview if you do not understand any part of the study.

Potential Risks:

- The interview should not cause you any harm, but some questions may cause you to think a lot.

Potential Benefits:

- Taking part in this study may not help you but by being in this study you could help to improve nursing research with families of adolescents with diabetes.
- As we said earlier, the information that you provide may be of help to others. The findings from the study can be used by nurses and doctors to provide better health care for families in similar situations.

Right to Withdraw:

If you decide to participate or not on this study it will not affect your access to services, such as health care. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort. However, once we mix your information with that of the other people in the study, we will no longer be able to take out your information. The deadline to ensure withdrawal of all of your data will be two weeks after the final interview is complete.

If you want to know the results of this study or have any questions about the study, which will be available by July 2021, please contact Pamela Farthing (306) 659-4199 or by email at

pamela.farthing@usask.ca

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board as being ethically sound on **(July 31, 2019) (Beh-REB ID #925)**. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Your completed consent form will be stored separately from the research data in locked drawers and/or a password-protected computer in Dr. Jill Bally's office at the College of Nursing, for at least five years. Only the research team will be able to look at this information.

We will give you a copy of what you have signed so you can look at it again if you need to. The researcher will also have a copy.

Name of Participant *Signature* *Date*

Name of Researcher *Signature* *Date*

Appendix J

Transcription Confidentiality Contract



Interdependence in Adolescents with Type 1 Diabetes

TRANSCRIPTION CONFIDENTIALITY CONTRACT

I have agreed to transcribe the recorded interview by a doctoral candidate enrolled in the College of Nursing at the University of Saskatchewan class.

I understand that **CONFIDENTIALITY** will be maintained as I will **NOT** talk about the content of this interview. Participants` surnames and names will remain **ANONYMOUS**. Pamela

Farthing and her co-supervisors Dr. Jill Bally and Dr. Donna Rennie will have access to the data.

I understand that no one else will be allowed to read the transcript.

This study has been reviewed by the University of Saskatchewan`s Behavioural Ethics Board and has been approved as being ethically sound on July 31, 2019 (Beh-REB #925). If I have any questions or desire further information, I may contact Pamela Farthing PhD candidate, College of Nursing, University of Saskatchewan at (306)659-4199 or by emailing her at pamela.farthing@usask.ca

I will **NOT** disclose the content of this interview to other people than the doctoral candidate and her co-supervisors _____ (Initials)

I acknowledge that the doctoral candidate, Pamela Farthing will receive a copy of this signed consent form. _____(Initials)

Transcriber`s Signature and Date_____

Doctoral Candidate`s Signature and Date_____

Appendix K

Demographic Questions for Adolescents with T1D

Please answer the following demographic questions (will be asked orally after the interview)

1. How old are you?
2. What is your gender?
3. What is your ethnicity? (If indicate Indigenous will ask them to specify [First Nations, Inuit, Metis])
4. Do you live urban/rural?
5. What type of insulins do you use?
6. What was your last HgbA1C?
 - 6 - 6.9%
 - 7 – 7.9%
 - 8 – 8.9%
 - 9 – 9.9%
 - Don't know
7. What is your current method of diabetes management? (2 or 3 injections per day, basal bolus, insulin pump, other)
8. Blood glucose monitor number of checks per day
 - 2
 - 3
 - 4
 - 5+
 - Continuous glucose monitor
 - Other _____
9. Are your parents married? Do you live with both your parents? If not living with both your parents how much time do you spend with mom? _____ How much time do you spend with dad? _____
10. How many times per week do you have low blood sugar? _____
What times of the day? _____
Ever passed out or had a seizure due to low blood sugar? _____

11. Have you been hospitalized for your diabetes? ___Yes ___No

Date (year) hospitalized: _____

Why were you hospitalized? _____

Appendix L

Demographic Questions for Parents of Adolescents with T1D

Please answer the following demographic questions (will be asked orally after the interview)

1. What is your relationship to the child with T1D?
 - Mother
 - Father
 - Stepmother/Stepfather
 - Grandparent
 - Other (please specify) _____
2. How old are you? (range 30-40, 40-50, 50-60, 60-70)
3. Do you live urban/rural?
4. What is your relationship status?
 - Single
 - Cohabiting
 - Married
 - Divorced - Do you share custody? How much time with Mother ____ with Father_____?
 - Other
5. What is your ethnicity? (If indicate Indigenous will ask them to specify [First Nations, Inuit, Metis])
6. How old was your child when they were diagnosed with T1D?
7. What was your child's last HgbA1C?
 - 6 – 6.9%
 - 7 – 7.9%
 - 8 – 8.9%
 - 9 – 9.9%
 - Don't know
8. What is their current method of diabetes management?
 - Multiple daily injections
 - Insulin pump
 - Blood glucose monitor
 - Continuous glucose monitor
 - Oral Medications

- Low Carbohydrate diet
- Other _____

9. What type of insulins do they use?

Appendix M

The Interview Guide for Adolescents

Briefing/Introduction to Interview:

Thank you for agreeing to talk to me today. What I hope to gain from our discussion today is knowledge about your experiences with type 1 diabetes (T1D), through your eyes. There are no right or wrong answers to the questions that I will be asking you. As I mentioned, this session will be recorded, as long as that is OK with you? Do you have any questions before we start the interview?

Interview Guide

I want to double check with you that you are OK to start the interview. Are you OK to start the interview questions now?

Let's start with talking a bit about you.

1. Tell me a little bit about yourself

Prompts if they aren't talking: What grade are you in? Do you have siblings, pets, a job? What are your interests? What activities are you involved in?

2. Can you please tell me a bit about when you were diagnosed with T1D

(How old were you? Where were you? What happened? Who was with you?)

Prompt: If they don't remember diagnosis (were too young) - Have you heard stories about when you were diagnosed? What does being diagnosed with T1D mean to you right now? How do you feel about having T1D?

3. How do you feel about caring for your diabetes?

4. How are you helped with your diabetes management?

Prompts: Who purchases your supplies? Who check on you? Who reminds you?

Additional question branched depending on how they answer:

First branch: You have said you don't have help to manage your diabetes... Do you think you should have to have help to manage your T1D? If so, with what tasks/what support do you feel you need that you aren't getting?

Second branch: You have said you don't need help to manage your T1D... Why do you think you don't need help?

Third branch: You have said your (whoever they say mom, friend, healthcare provider) helps you to manage your T1D. How would you describe that help? Can you tell me a little bit about how you find your (friend, parent, healthcare provider etc) to be helpful?

5. I'm interested in finding out more about who helps you with your diabetes.

Who are the people you go to when you need help with your diabetes? Please tell me more about that.

6. If you could use a few words to describe a helpful relationship in caring for your diabetes, what would you say?

7. When you are caring for your diabetes, is there anything that others do that is not helpful?

8. You've told me a bit about your diabetes care.

Can you please tell me how involved you've been in that care?

Can you tell me a little bit about how you feel about your involvement in your diabetes care?

At what age would you say you became more involved?

How did this happen?

How did it make you feel?

How is that working for you? Is there anything you would do differently?

If the participant describes that they are self-managing or are being encouraged to self-manage their diabetes, then I will ask what they think it means to 'self-manage'.

I will not stop the conversation well let it continue as it happens before proceeding to debriefing.

- Mention some of the main points learned from the interview
- I think we have covered a lot of information. Is there anything else you would like to bring up or ask about, before we finish the interview?"

Thank the participant for their time, ensure they have a copy of the signed consent.

Appendix N

The Interview Guide for Parents

Briefing/Introduction to Interview:

Thank you for agreeing to talk to me today. What I hope to gain is knowledge about your experiences with caring for your teenager's type 1 diabetes, through your eyes. There are no right or wrong answers to the questions that I will be asking you. As I mentioned, this session will be recorded, if that is OK with you? Do you have any questions before we start the interview?

Interview Guide

1. How is your day going so far? Can you please tell me a little bit about yourself? What is your occupation?
2. Can you please tell me a little bit about the time your teenager was diagnosed with T1D?

Prompts

Where were you?

What happened?

Who was with you?

How did you feel? (scared, overwhelmed, blinded, well supported, fine)

3. Can you please tell me how your child's diabetes managed day to day?

Prompts

What type insulin delivery?

Who is involved in doing your child's injections/calibrations food intake (carb counting) exercise sick day management.?

4. Can you please tell me how well you think that your child's diabetes is being managed? How do you know? Explain

5. Can you tell me how you are helped with your child's diabetes management?

Prompts: Who purchases supplies? Who check on them? Who reminds them?

Next question branched depending on how they answer:

First branch: You have said your child doesn't have help to manage their diabetes... Do you think you they should have help to manage their T1D? If so, with what tasks/what support do you feel they need that they aren't getting?

Second branch: You have said your child doesn't need help to manage their T1D... Why do you think they don't need help?

Third branch: You have said you (or whoever else they indicate) helps your child to manage their T1D. How would you describe that help? Can you tell me a little bit about how you (or whomever) is helpful?

6. Is there anything that you or others do that isn't helpful for your teen's T1D management (teen doctor, peers, family)? Is it possible to manage T1D without any help? Why or why not?

7. I'm trying to do research about "interdependence", which means working together as a team towards a 'goal'. Do you think you experience "interdependence" regarding your diabetes management? Why or why not?

How does interdependence apply to T1D management?

Do you have a team? What's the goal

Feel support without control/fear

8?? Can you please tell me when your child became more involved in the care of their diabetes?

9?? How did their changing involvement in their care make you feel? (Parents taking on less involvement, child taking on more – how did/does that make them feel)

If the participant describes that their child is self-managing their diabetes or being encouraged to self-manage their diabetes, then will ask what they think it means to ‘self-manage’.

I will not stop the conversation well let it continue as it happens before proceeding to debriefing.

- Mention some of the main points learned from the interview
- I think we have covered a lot of information. Is there anything else you would like to bring up or ask about before we finish the interview?”

Thank the participant for their time, ensure they have a copy of the signed consent.

Appendix O

Discussion Guide for Interview #2

Briefing/Introduction to Interview:

Thank you for agreeing to talk to me again today. What I hope to do today is mainly to go over some areas I'd like to check and perhaps clarify from our first interview. Remember there are no right or wrong answers to anything we are discussing. As I mentioned last time, this session will also be recorded, as long as that is OK with you? Do you have any questions before we start our discussion?

This second interview is a follow up to the first interview and as per grounded theory methodology any questions or points of clarification will arise from what is discussed in the first interview so cannot be written out entirely at this point.

Questions will be following this type of format: In the first interview you mentioned ... Can you please tell me more about that?

Also, a line of question in the second interview will include building off of any discussion in the first interview of 'helping' or 'teamwork'.

A question such as this: I've done some reading and sometimes this helping or teamwork is referred to as interdependence. What does this term mean to you?

I'm trying to do research about a word that means teamwork, called "interdependence", if you think "independent" means...what do you think "interdependence" means? Again there is no right or wrong answer here, I just want to know what you think.

Do you think you experience "interdependence" regarding your diabetes management? Why or why not?

In the first interview I asked you to describe a helpful relationship and you use words like caring and compassionate. To me these words are characteristics of a helpful relationship not really a word or phrase that labels a helpful relationship, so I want to spend more time trying to come up with this word or phrase. Let's think of other helpful relationships not related to diabetes, what would these be?

Do you have words that name these relationships?

Which of these words could you now apply to the helpful relationships you have to manage your diabetes?

When people are in helpful relationships, all people involved benefit in some way otherwise it's not much of a relationship. How do all the people you mentioned benefit you?

Are there things that you do or don't do that benefits them regarding the management of your diabetes?

It seems that you and your helpers want to manage your diabetes well, you all have the same goal, is that correct?

What word best describes a group of people working towards the same goal?

What are all the things you would have to do or not do so that you could manage your diabetes all by yourself?

PARENT

During the first interview you were talking about how he/she doesn't like to have a blood sugar below 6 because he/she feels too shaky and that you don't want him/her to go too high because

of her behavior and long-term complications, have you ever discussed with your son/daughter what the target is and why that target is there? Why or why not?

She seems to be relying very heavily on you to help manage his/her diabetes, why do you think that is so?

What do you think would happen to him/her if you didn't help? Does he/she know that?

What would he/she have to do or not do so that he/she would not need your help anymore? Do you think that it is possible for him/her to be totally independent of you to manage her diabetes? Why or why not?

What word or phrase would you use to label a mutually beneficial relationship? Are you, your son/daughter and anyone else that helps achieving this word? Why or why not?