Type 1 diabetes self-management in hospital: a constructivist grounded theory

By

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Table of Contents

List of Figures

List of Tables

Thesis Summary

Every day in Australia, nine people are newly diagnosed with type 1 diabetes (T1D), with prevalence of the chronic condition on the increase worldwide. T1D is an autoimmune disorder which destroys the ability of the pancreas' beta cells to produce insulin, leading to high plasma glucose levels. Currently, this chronic condition is unpreventable and incurable and requires those living with T1D to self-manage using blood glucose monitoring (BGM), insulin administration, dietary intake management and undertaking physical activity. This intricate and complex daily self-management routine also incorporates timing of all management tasks, decision-making and problem-solving around those tasks and implementing treatment in response to alterations of blood glucose levels (BGLs). Over time those living with T1D become known as expert self-managers. However, on admission to hospital people with T1D are often required to relinquish their self-management and their expertise related to their chronic condition is overlooked by health professionals.

Currently there is limited research on T1D self-management in hospital, therefore a constructivist grounded theory approach was used to explore the influence of hospitalisation on T1D self-management in Australia. A focus group and in-depth interviews were conducted with adults living with T1D to interpret and explain their meanings of self-management while in hospital and their subsequent actions. The generation and analysis of data were guided by Charmaz's constructivist grounded theory methods which include line by line and focused coding and constant comparative analysis.

The application of the core tenets of grounded theory led to the construction of the substantive theory which explains T1D self-management in hospital from the perspective of the participants. The participants found their interactions with health professionals in hospital led the participants to recognise the risks they faced in relation to their T1D management and forced them to take action to prevent harm being caused to them. As a consequence of the health professionals' actions in hospital, participants' reliance on their *everyday* T1D self-management expertise was required. The overall substantive grounded theory constructed during this study was *The Social Construction of Keeping Self Safe.*

While there are some similarities to existing research, the findings of this study are unique as there has been no previous exploration of the experience of the person with T1D in hospital, nor generation of a theory to explain the phenomenon. Furthermore, with a current focus on safety and quality in health care in Australian hospitals, this study found participants with T1D felt unsafe while in hospital and as a consequence, they found themselves having to take responsibility for maintaining their safety, as they could not rely on being kept safe by the actions of health professionals in hospital. This grounded theory therefore enables an increased understanding of the requirements of people with T1D in hospital and identified areas for improvement, particularly in relation to the care provided by health professionals. The study makes recommendations in relation to suggested improvements for current practices in Australian hospitals such as the development of self-management policies, additional education requirements for health professionals and further research.

Therefore, my original contribution to knowledge was to generate a theory that explains T1D self-management in hospital. This thesis contributes to an enhanced understanding of the experience and meaning of self-management for the person living with T1D while in hospital.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed.......Rebecca Munt....................

Date..........5 September 2019................

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First and foremost I would like to thank the people living with type 1 diabetes (T1D) who gave up their valuable time to share their experiences of being in hospital for this study. As the saying goes ‘nothing about us without us’ could ever have been truer, as without these generous individuals this PhD would not have been achieved. A special thank you also to those people in the T1D community who supported my research and advertised this research on their social media sites for participant recruitment. Thank you also to Diabetes Victoria, Type 1 Diabetes Network and ADEA for their support in recruitment of participants for this study.

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To my friends who always asked how is that PhD going? well the answer is it is done so put the champagne on ice!

Works Arising from this Thesis

Conference presentations

Munt, R, Hutton, A, Zannettino, L & Giles, T 2018, ‘Type 1 diabetes mellitus (T1DM) self-management in hospital: a constructivist grounded theory’, Australasian Diabetes Congress, Adelaide, 22- 24 August.

Munt, R 2018, ‘The experience of type 1 diabetes mellitus (T1DM) self-management in hospital: a constructivist grounded theory’, SA Nursing and Midwifery Research Symposium, Adelaide, May 17.

Munt, R 2014, ‘Diabetes: A Patient Perspective’, Southern Adelaide Local Health Network Diabetes Update for Nurses and Midwives, Flinders Medical Centre, Adelaide, April 11 2014.

Munt, R 2013, ‘Type 1 Diabetes Mellitus management in hospital: the person’s experience’ International Diabetes Federation World Diabetes Congress 2013, Melbourne, December 2 – December 4, 2013. Peer reviewed poster presentation.

Munt, R 2013, ‘Type 1 Diabetes Mellitus management in hospital: the person’s experience’, Australian Diabetes Society (ADS)/ Australian Diabetes Educators Association (ADEA) Annual Scientific Meeting, Sydney Convention & Exhibition Centre, August 28 – 30.

Publications

Munt, R, Hutton, A, Zannettino, L & Giles, T 2018, ‘The experience of type 1 diabetes self-management in hospital: a constructivist grounded theory’ *Australian Diabetes Educator*, vol. 21, no. 4. (see Appendix 19 on page 282)

Awards

2018 *Awarded Roche Best Abstract Award* **Munt, R,** Hutton, A, Zannettino, L & Giles, T 2018, ‘Type 1 diabetes mellitus (T1DM) self-management in hospital: a constructivist grounded theory’, Australasian Diabetes Congress, Adelaide, 22- 24 August.

2013 *Awarded ADEA Best Oral Presenter* for **Munt, R** 2013, ‘Type 1 Diabetes Mellitus management in hospital: the person’s experience’, Australian Diabetes Society (ADS)/ Australian Diabetes Educators Association (ADEA) Annual Scientific Meeting, Sydney Convention & Exhibition Centre, August 28 – 30.

Prologue

From 2006 until 2018 I was employed at Flinders University as a Lecturer in Nursing, with a Diabetes focus. My area of research focused on diabetes and my teaching was predominantly in the post graduate Diabetes Management and Education specialisation. In addition, previously living with a person with T1D influenced my decision to choose to research an area related to T1D. Therefore, my research was influenced by both a professional and personal interest in self-management of T1D. However, the initial impetus for the research topic was influenced by the following quote from a person living with T1D who had recently been hospitalised.

> 'I've had diabetes since I was nine. That's 26 years. They (nurses) treat me like I don't know anything. They took away my food that I kept for hypos 'because you're diabetic'. I had a hypo before lunch yesterday because they gave me Actrapid at 11 and lunch didn't come until 12.30. I had nothing to fix it and they gave me milk to treat it. They just wouldn't listen' ('G' 2006).

Subsequent interactions with people who live with T1D, at Diabetes South Australia, resulted in further anecdotal evidence suggesting that some health professionals discredit the person with T1D's knowledge about their daily diabetes management whilst admitted to hospital. Preliminary discussions with people living with T1D confirmed aspects of the above quoted hospital experience to be reflective of their experiences while being hospitalised with an admission diagnosis unrelated to their T1D.

In addition, my professional experience supported the suggestion there may be a number of constraints on a person being able to self-manage in hospital. As a Registered Nurse in clinical practice, I witnessed medical and nursing staff 'telling' patients with T1D how they should manage their condition when admitted with an unrelated condition. These health professionals were observed dismissing the person's legitimate concerns relating to insulin administration times, blood glucose monitoring and hypoglycaemia treatment, possibly bringing into question their knowledge of contemporary evidence-based diabetes management. Therefore, when a person with T1D is admitted to hospital their diabetes management may be controlled by an 'ideal' medical model of care rather than by the individual's own self-management routine. These events led me to undertake a preliminary exploration of the literature to determine whether these issues raised by people with T1D, which had also been witnessed in practice, had been previously researched. It appeared these issues had not been previously researched despite the recognition by Weiss (2006) of the inpatient being identified an effective 'tool' for managing their diabetes in hospital.

> 'It is sometimes easy to overlook another effective tool for inpatient diabetes management – the patient' (Weiss 2006, p. 951).

This thesis is the result of eight years of part time research into the experience of self-management for adults with T1D when admitted to an Australian hospital for a primary admission diagnosis other than their T1D.

Acronyms

ADA	American Diabetes Association
ACSQHC	Australian Commission on Safety and Quality in Health Care
ASQGHC	Australian Safety and Quality Goals for Health Care
ADEA	Australian Diabetes Educators Association
ADS	Australian Diabetes Society
AIHW	Australian Institute of Health & Welfare
BGL(s)	Blood glucose level(s)
BGM	Blood glucose monitoring
CASP	Critical Appraisal Skills Program
CGM	Continuous glucose monitoring
CGT	Constructivist grounded theory
CSII	Continuous subcutaneous insulin infusion
DAFNE	Dose Adjustment for Normal Eating
DAS3	Diabetes Attitude Questionnaire
DBKT	Diabetes Basic Knowledge Tool
DCCT	Diabetes Control and Complications Trial
DCCT/EDIC	Diabetes Control and Complications Trial/ Epidemiology of Diabetes Interventions and Complications
DMKAT	Diabetes Management Knowledge Assessment Tool
DSRT	Diabetes Self-Report Tool
DKA	Diabetic Ketoacidosis
ES	Environmental sensitivities
HbA1c	Glycated haemoglobin or glycosylated haemoglobin
HBM	Health Behaviour Model
HCPRDU	Health Care Practice Research and Development Unit
HSCIS	Health and Social Care Information Centre
IDF	International Diabetes Federation

IOM	Institute of Medicine
IPT	Insulin pump therapy
JBDSICG	Joint British Diabetes Societies for Inpatient Care Group
MDBKT	Modified Diabetes Basic Knowledge Tool
MDI	Multi daily injections
NDSS	National Diabetes Services Scheme
NHMRC	National Health & Medical Research Council
NICE	National Institute for Healthcare and Excellence
PMT	Protection Motivation Theory
SA	South Australia
SBREC	Social and Behavioural Research Ethics Committee
T1D	Type 1 diabetes
T1DN	Type 1 Diabetes Network
T2D	Type 2 diabetes
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Notation used throughout thesis

Various notations were used throughout this thesis to accentuate or explain language. For ease of understanding, these notations are listed below:

Italics are used to accentuate a title of a text with the in text reference acknowledging the author of the text.

Italics are used to highlight the categories and the core category of *Keeping Self Safe* throughout the body of the thesis.

Individual participant data is identified in the thesis by their pseudonym and then either Focus Group (FG) or Interview and interview number. For example, (Trish Int. 5).

To provide an explanation or context to what a participant is referring to in their data, brackets are used, and my words are not italicised. For example, *generally with diabetes you have this spike* (increased BGL).

If a small section of a participant quote is used within a sentence in the thesis, it is italicised, and the participant pseudonym is acknowledged in brackets at the end of the sentence.

The use of .... indicates a break in the quotation from the participant from either the interview or focus group data.

Chapter One: Introduction

1.1 Chapter overview

Type 1 diabetes (T1D) is a chronic condition that requires the person to undertake complex daily self-management to remain well. This thesis provides an interpretation of the self-management experience for adults living with T1D while they are in hospital. Chapter one provides an overall introduction to the thesis that explored the experience of T1D self-management in hospital. This chapter provides the background to the issue being explored and describes the purpose, aim and significance of the study. The chapter also provides a brief introduction to the chosen methodology for the study. An overall synopsis of the thesis is also included in this chapter.

1.2 Background

The following section of this chapter provides the background information for the study. The background includes a definition of T1D, a discussion on the different definitions of self-management, how people with T1D self-manage their chronic condition and what is currently known about T1D self-management in hospital.

1.2.1 Type 1 diabetes

Type 1 diabetes (T1D) is an autoimmune disorder that destroys the ability of the pancreas' beta cells to produce insulin, leading to high plasma glucose levels (Drury & Gatling 2005; Australian Institute of Health & Welfare (AIHW) 2014; Diabetes Australia 2015). As a consequence of this autoimmune disorder, individuals become reliant on subcutaneous delivered insulin for survival (Dunning 2014; Simmons & Michels 2015; Diabetes Australia 2015a). Currently T1D is unpreventable and incurable (Craig et al 2011; AIHW 2014). Worldwide incidence data collected by the International Diabetes Federation (IDF) suggests that 497,100 children aged 0 – 15 are living with T1D (IDF 2013). However, data is not recorded for people over the age of fifteen as most prevalence studies conducted on adults do not distinguish between T1D and type 2 diabetes (T2D) (IDF 2015). The World Health Organization (WHO 2016) suggested that the worldwide incidence of T1D is difficult to measure due to large variations in occurrence and prevalence recordings through a variety of standardised registries. Furthermore, the distinction between T1D and T2D can require sophisticated laboratory tests of pancreatic function to obtain a correct diagnosis (WHO 2016). However, it is recognised that there has been a steady increase in the prevalence of T1D worldwide, making T1D a 'significant societal healthcare problem' (Dadlani et al 2017, p. 572).

According to the National Diabetes Services Scheme (NDSS), 117,423 Australians were registered with a diagnosis of T1D in 2015 (NDSS 2015). By May 2019 this number had risen to 119,751 Australians (NDSS 2019). Currently nine people are diagnosed with T1D each day in Australia, with a total of 3360 people newly registered to the NDSS from March 2018 – March 2019 (NDSS 2019). Comparatively in the period between March 2014 -2015 the number of people who were newly diagnosed was 3064 (NDSS 2015). The NDSS data supports the increasing prevalence of T1D in Australia.

1.2.2 Definition of self-management

The concept of self-management has emerged over the last 30 years as significant for the management of chronic conditions (Battersby, Lawn & Pols 2010; Song 2010). Originally, the concept of self-management was health care driven and in response to the burden of chronic conditions as health professionals came to recognise that they could not always be available to make decisions for these people (Battersby, Lawn & Pols 2010).

There are numerous definitions of self-management and there is no clear consensus on how it should be defined (Song 2010). As a prolific researcher in the area of self-management, Kate Lorig (1993, p. 11) indicated that self-management enables:

> 'participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practise new health behaviours, and to maintain or regain emotional stability.'

Lorig's (1993) perspective of self-management revolves around the individual, their informed decision-making capacity and what actions they could undertake to maintain wellness and emotional stability. The Centre for Advancement of Health (1996) stated that self-management:

> 'involves (the person with a chronic disease) engaging in activities that protect and promote health, monitoring and managing the signs and symptoms of illness, managing the impact of illness on functioning, emotions and interpersonal treatments and adhering to treatment regimes.'

While the Centre for Advancement of Health (1996) focused on what the individual is required to do, they also added that in order to self-manage, the individual was required to adhere to treatment regimes prescribed by health professionals. In more recent times, there has been a shift from the notion of patients 'adhering to treatment regimes' to patients collaborating with health professionals (Centre of Advancement of Health 1996; Wellard 2010). This shift enables individuals to become more knowledgeable about their condition and encourages them to participate in decision-making about their condition, which is pivotal to effective self-management (Ciechanowski & Katon 2006; Henderson et al 2014). In line with this shift, Lin et al (2008) determined that self-management for the person with a chronic condition involves a collaborative process with health professionals and significant others, rather than adhering to treatment regimes. They defined self-management as:

> 'an active and flexible process in which patients regulate their actions, collaborate with their health care providers and significant people to develop strategies for achieving expected goals and perform preventable and therapeutic health related activities' (Lin et al 2008, p.370).

Initially Kralik et al (2004, p. 260) described self-management as making 'reference to the activities people undertake to create order, discipline and control in their lives'. However, in 2009 she simplified her description of self-management to be the actions and decisions individuals make on a daily basis to manage their illness (Kralik 2009).

While the definition of self-management has altered over the last 30 years, the core focus is still on the activities of the individual with the chronic condition (Battersby, Lawn & Pols 2010). The reality for the person with T1D is that if they are unable to effectively self-manage their diabetes, their lives are potentially at risk from hypoglycaemia or Diabetic Ketoacidosis (DKA).

1.2.3 Type 1 diabetes self-management

The majority of adults with T1D are responsible for their daily self-management which includes blood glucose monitoring (BGM), insulin administration, following healthy eating principles and undertaking physical activity (Dunning 2014; Diabetes Australia 2015; Diabetes Australia 2015a; Visekruna, Edge & Keeping-Burke 2015). Self-management is required by individuals with T1D for survival and to maintain their individualised BGL target ranges, known as normoglycaemia. In addition, self-management is required to reduce the potential of long term microvascular, macrovascular and neurologic complications that are associated with hyperglycaemia (The Diabetes Control and Complications Trial (DCCT) Research 1993; DCCT/ Epidemiology of Diabetes Interventions and Complications (EDIC) Study Research Group 2005).

The significance of maintaining individualised target range glycaemic levels highlights the importance of day to day self-management of T1D, which has been acknowledged as the cornerstone of diabetes management (Toljamo & Hentinen 2001; Nafees et al 2006). This intricate and complex daily self-management routine also incorporates timing of all management tasks, decision-making and problem-solving around those tasks and implementing treatment in response to alterations of blood glucose levels (BGLs). Individuals with T1D are known to typically make over 100 decisions on a daily basis related to their self-management (Hendrieckx et al 2016).

Researchers suggest that self-management comprises up to 98% of T1D management in the outpatient setting (Toljamo & Hentinen 2001; Munt & Hutton 2012; Dunning 2014) with the other 2% comprises interactions with health professional at appointments. Having a chronic condition is seen as pervasive. The individual, not the health professional, has to cope with all that the condition entails, including preventative measures, symptom management, adjustments to lifestyle and dealing with the emotional consequences. On occasions, random unidentified factors are known to impact on T1D self-management which, as McIntyre et al (2010, p. 639) suggests, makes T1D ‘a profoundly vexatious chronic’ condition. Over time, people are known to become experts in their own T1D self-management through years of lived contextual experience (Paterson & Thorne 2000; Thorne, Ternulf Nyhlin & Paterson 2000).

1.2.4 Admission to hospital with T1D

People with T1D will be admitted to hospital for a variety of primary admission diagnoses, other than out-of-target range glycaemic control (van Zyl & Rheeder 2008; Colagiuri et al 2009; Craig et al 2011; Health and Social Care Information Centre (HSCIC) 2013; Mendez & Umpierrez 2017). These primary admission diagnoses can be a consequence of microvascular and macrovascular complications that can develop over time (Colagiuri et al 2009), due to the requirement of elective surgery, or due to exacerbation of a medical condition. In 2015 – 2016, approximately 59,900 hospitalisations were recorded in Australia with T1D being either a principal or additional diagnosis (AIHW 2018). Within these recorded episodes, 45,300 had T1D as an additional diagnosis, rather than the primary admission diagnosis (AIHW 2018). Since the 2012- 2013 collected data, there has been a comparative increase of 6350 hospital admissions where T1D is an additional diagnosis demonstrating an increased prevalence of recorded episodes (AIHW 2014).

In 2011, an audit of inpatients with diabetes was conducted in the United Kingdom (HSCIC 2013). The audit data collected in England identified that 32% of people admitted with T1D required specific management of their diabetes, while 68% were admitted for other medical conditions or a non-medical/surgical reason (HSCIC 2013). These findings provide additional information on admission diagnoses for people with T1D. Regardless of the primary hospital admission diagnosis, adults with T1D require their daily T1D self-management to continue while they are in hospital.

1.2.5 T1D self-management in hospital

It is recognised that on admission to hospital, people with T1D are often required to relinquish their self-management responsibility (Cohen et al 2007; Mabrey & Setji 2015). Mabrey and Setji (2015) and Shah and Rushakoff (2015) identified that it is common practice for health professionals to take over T1D management from the individual in hospital.

The research literature identifies issues that may impact on the experience of self-management for the person with T1D in hospital. These issues include the person's expectations of self-management while in hospital that are often shaped by their previous hospitalisations and their interactions with health professionals during those hospitalisations (Wilson, Kendall & Brooks 2006; Munt 2009; Munt & Hutton 2012). In addition, the hospital environment itself is seen to impact self-management through the influence of 'rules' around T1D management and the limited communication and information sharing between health professionals and patients with T1D (Munt 2009; Munt & Hutton 2012).

Munt (2009) and Mabrey and Setji (2015) indicated that people with T1D are knowledgeable and capable of self-managing their diabetes in hospital due to years of lived contextual experience. In addition, the participants in a study by Munt (2009) indicated an interest in continuing to self-manage their T1D in the hospital environment. Munt's (2009) study found a number of factors impacted on self-management in hospital for the patient with T1D, including the patient's perspectives of self-management, their expectations of self-management in hospital, their actual experience of self-management in hospital and the impact of the hospital environment on self-management.

1.3 Purpose of the study

The purpose of this study was to construct a substantive grounded theory about T1D self-management in hospital. Specifically, the aim of the study was to explore the self-management experiences of the adult with T1D in Australian hospitals with a primary admission diagnosis other than T1D.

1.4 Significance of the study

The significance of this study is based on five key aspects. They are the:

1. need to improve current understanding of T1D self-management in hospital;
2. increasing emphasis on partnering with consumers in health care;
3. patients' unique insight into their experience of care;
4. lack of Australian T1D self-management guidelines; and
5. need to align with the goals of the Australian National Diabetes Strategy 2016–2020 (Australian Government 2015).

1.4.1 The need to improve current understandings of T1D self-management in hospital

Overall, the issue of T1D self-management in hospital appears to have been under-researched (Munt 2012). A preliminary review of the current literature found there is limited published research on the individuals' experiences of self-managing their T1D while in hospital (see Chapter 2 on page 14). The lack of available research suggests that the experience of T1D self-management in hospital has not been previously explored in-depth, thus supporting the need for this study.

An Honours study on the phenomenon provided insight into the T1D self-management experiences of a small cohort of participants in a specific ward in a specific hospital (Munt 2009). The specific and small sample in the Honours study, combined with the dearth of literature on the topic of T1D self-management in hospital, suggests that further exploration of this phenomenon is warranted, particularly research that involves a larger cohort of participants from a range of wards and hospitals around Australia (Munt 2009). In addition, no previous theory has been generated about the self-management experiences for adults with T1D in hospital which supports the significance of this PhD study and the use of a CGT methodology (Charmaz 2014).

1.4.2 The increasing emphasis on partnering with consumers in health care

Safety and quality have become significant concepts for health care delivery and health care reform in Australia (Australian Commission on Safety and Quality in Health Care (ACSQHC) 2012). The three main Australian Safety and Quality Goals for Health Care (ASQGHC) (ACSQHC 2012) are: safety of care, appropriateness of care and partnering with consumers. The ACSQHC identified that partnering with consumers is significant as consumer centred care and partnerships have been associated with a decrease in re-admission rates and hospital acquired infections and reduced length of stay (ACSQHC 2012a). According to the ACSQHC, health professionals currently believe they understand, value and provide consumer centred care (ACSQHC 2012a). However, patient feedback to the ACSQHC suggests that their experiences do not match the beliefs of health professionals (ACSQHC 2012a). The intention of the current study was to provide further understanding about the experiences of the consumers' specific to their T1D self-management in hospital in order to increase opportunities for collaboration and partnership.

There are two desired outcomes identified within the *Partnering with Consumers* document, which are relevant to this study (ACSQHC 2012a). The first outcome is ‘Consumers are empowered to manage their own condition, as clinically appropriate and desired’, which suggests support for self-management (ACSQHC 2012a, p. 1). The second outcome is related to communication between the patient and health care providers: ‘Consumers and healthcare providers understand each other when communicating about care and treatment’ (ACSQHC 2012a, p. 1). Through an exploration of people’s self-management experiences of their T1D in hospital, the current study intended to shed light on the degree to which these outcomes have been achieved from the perspective of the research participants.

1.4.3 The patient’s unique insight into their experience of care

Patients are in a unique position to provide insight into the care they experience in hospital (Harrison, Walton & Manias 2015). Harrison, Walton and Manias (2015) suggested that the majority of existing published studies on patients’ hospital experiences were conducted by health professionals using quantitative surveys, with the focus on patient satisfaction rather than experience. In their evidence check review of qualitative studies, Harrison, Walton and Manias (2015) found that studies focusing on patients’ experiences in Australian hospitals were sparse and further studies are required to address identified gaps. The review found that a limited number of studies focused on chronic condition management in hospital and that most of these studies did not seek to develop a theoretical understanding of patients’ experiences in hospital (Harrison, Walton & Manias 2015). Using a CGT approach for the study will assist in addressing the gaps identified by Harrison, Walton and Manias (2015) by constructing a substantive theory on the persons’ T1D self-management experience in hospital. Moreover, the findings of the proposed study will contribute to knowledge about consumer experiences and views, which is necessary to inform health professionals about the needs of people with T1D during hospitalisation and to improve service delivery (Perry et al 2011).

1.4.4 The lack of Australian T1D self-management guidelines

Currently in both the United States of America (USA) and the United Kingdom (UK) there are standards and guidelines for T1D self-management in hospital. The American Diabetes

Association (ADA) published its *Standards of Medical Care* in 2015, which include *Diabetes Care in the hospital, Nursing home and skilled nursing facility* and includes the sub-heading of *Self-management in the hospital* (ADA 2015). The standard indicates support for self-management for those who are deemed capable only if the patient and physician, in consultation with nursing staff, agree that self-management is appropriate (ADA 2015, S. 82). However, no research is referred to in the standard to support ADA's position for self-management in hospital, which indicates there is limited research evidence available to support this aspect standard.

The UK's National Institute for Healthcare and Excellence (NICE) guidelines about T1D management in adults includes care of the adult with T1D in hospital (NICE 2015). The guidelines support the adult with T1D to self-administer insulin if they are willing and able and suggest that the adult's T1D expertise is to be respected and integrated into their BGM and insulin administration (NICE 2015). Like the ADA (2015), these guidelines were not supported by research but were developed using the expertise of the guideline development group (NICE 2015). As these guidelines were developed for the USA and UK health systems and are expert opinion based, [1]it may be difficult and inappropriate to adapt these guidelines to an Australian context. In addition, these standards and guidelines do not shed light on how people experience their T1D self-management in hospital and/or whether they perceive that there are appropriate supports provided to enable them to self-manage in hospital.

Currently, Australia has no national guidelines available for T1D self-management in hospital. Craig et al (2011) developed the first Australian evidence-based guidelines for clinical care across the lifespan to address the needs of individuals with T1D. However, T1D management as an inpatient is absent from these guidelines. Previous clinical practice guidelines included hospital management, specifically focusing on protocols for health professionals to manage surgery and fasting for children and adolescents with T1D (National Health & Medical Research Council (NHMRC) 2005).The 2011 guidelines, while developed to address the clinical care requirements

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[1] Hierarchy of evidence indicates the opinion of authorities or reports of expert committees are the lowest ranked levels of evidence while qualitative studies are ranked above the opinion of experts (Liamputtong 2017, p.6).

across the lifespan for people with T1D, do not include hospitalisation, reinforcing the limited availability of evidence on the studied phenomenon. In addition, the Australian Diabetes Society's (ADS) perioperative guidelines (ADS 2012) do not include any support or evidence for self-management in hospital. As this study will provide an understanding of patients' experience of T1D self-management in hospital, it has the potential to influence future policy and guidelines in Australia.

1.4.5 The need to align with the goals of the Australian National Diabetes Strategy

In 2015, the Australian Government released the Australian National Diabetes Strategy for 2016 – 2020 (Australian Government 2015). Two goals of the strategy specific to the provision of high-quality hospital care are relevant to the significance of the proposed study. The first strategy suggests the consideration of linking with the ACSQHC to provide clinical care standards for diabetes to ensure the delivery of a consistent approach to appropriate care in hospital (Australian Government 2015, p. 19). The second strategy is the provision of education and training to health professionals who provide care to patients with T1D while in hospital. The implications and recommendations for practice from this study have the potential to inform the delivery of both of these strategies (Australian Government 2015). Another component of the Strategy is to strengthen care through research by specifically examining barriers to best practice and the availability of appropriate health care (Australian Government 2015). The recommendations developed from this study will provide direction for policy and best practice in relation to providing appropriate care and support for people with T1D in hospital.

1.5 Chosen Methodology

In order to explore the person's experience of T1D self-management in hospital, a qualitative methodology was deemed appropriate. Qualitative methodology was chosen as the phenomenon has not been rigorously explored and there is a known gap in theory developed in relation to people's experiences of chronic conditions in hospital (Harrison, Walton & Manias 2015). An interpretive paradigm was specifically selected to meet the aim of the study and a constructivist grounded theory (CGT) method by Kathy Charmaz was chosen as the most appropriate to meet the purpose of the study (Charmaz 2006; 2014). Social constructionism is the underlying epistemology of this interpretive study with symbolic interactionism as the theoretical underpinning (Charmaz 2014). The use of social constructionism enables an understanding of how the participants construct their experiences in hospital through an interpretation of the generated data (Charmaz 2014). Symbolic interactionism provides a lens through which to view the ways in which participants allocate meaning to their experiences through interactions with others (Charmaz 2014). Furthermore, both the hospital and chronic conditions are socially constructed phenomena and the interactions people have within the hospital shape the ways that society understands and constructs the patient in hospital. The study's chosen methodology, its epistemology and theoretical underpinning are discussed in detail in Chapter three.

1.6 Synopsis of Thesis

Chapter one began with the background to T1D, definitions of self-management, the specifics of T1D self-management and T1D self-management in hospital. The purpose and aim of the study were stated along with its significance. The selected methodology was briefly introduced and a synopsis of the thesis is presented below.

Chapter two presents the preliminary literature review and its justification specific to the study. Main findings of the reviewed literature around T1D self-management in hospital are presented under the headings of: *Management of T1D in hospital*, *Health professionals' knowledge of diabetes* and *The expert patient*.

Chapter three discusses the selected interpretive research methodology, CGT. The chapter provides a discussion of the epistemology of social constructionism along with the theoretical underpinning of symbolic interactionism. In addition, the chapter includes a justification for the chosen methodology to meet the overall purpose and aim of the study.

Chapter four presents the methods used to generate the data with the participants in the study. The chapter discusses the generation and analysis of the data through the application of constant comparative analysis. Specific details about how the substantive grounded theory was constructed are also discussed. In addition, ethical considerations for the study are described.

Chapter five is the first of four findings chapters. This chapter introduces the substantive grounded theory and conceptual model and provides an overview of the study participants.

Chapters six and seven present two major categories of the substantive grounded theory. Chapter six presents the *Hospital influences on T1D self-management* in hospital and Chapter seven presents the *Everyday influences on T1D self-management* in hospital.

Chapter eight presents the theoretical perspective of the substantive grounded theory of *Keeping Self Safe* and explains how the theory is situated within existing knowledge and how it adds new knowledge to improve understandings of the explored phenomenon.

Chapter nine provides the overall contribution of the study to knowledge as well acknowledging the study's strengths and weaknesses. In addition, the chapter includes the implications and recommendations for practice, education, policy development and future research.

Throughout the thesis, I refer to myself in the first person, which is not necessarily an accepted convention in academic writing. However, with CGT method the researcher is positioned as a co-constructor of knowledge through data generation, data analysis and theory development (Charmaz 2006; Birks & Mills 2011; Charmaz 2014). Therefore, in order to acknowledge my contribution to the research I use my own voice, which is in line with the CGT method used.

1.7 Chapter summary

Chapter one provided an introduction to the study, the background to the research problem, along with the purpose and significance of the study. T1D is a chronic condition that requires people to self-manage in order to survive. However, there has been minimal research on the person's experience of T1D self-management in hospital and the current available evidence suggests that diabetes management in hospital is less than ideal. The purpose of this study was to explore adults with T1D experience of self-management in hospital in order to inform policy and practice. In addition, the study contributes new knowledge through the construction of a substantive grounded theory on T1D self-management in hospital which is described in Chapter eight. The following chapter will provide a preliminary review of the literature related to T1D self-management in hospital.

Chapter Two: Preliminary literature review

2.1 Chapter Overview

Chapter one provided an introduction to the study, the background to the research problem along with the significance and purpose of the study. Chapter two provides a preliminary review of the literature related to type 1 diabetes (T1D) self-management in hospital. The reviewed literature is predominantly from an international perspective with minimal Australian research available. The chapter begins with a discussion of the differing perspectives about the use of literature in grounded theory method and provides a justification for this preliminary literature review. A summary of the reviewed literature is included along with a critique of the reviewed studies. The findings of the reviewed studies were thematically analysed and are presented under three headings; *Management of T1D in hospital*, *Health professionals' knowledge of diabetes* and *The expert patient*. The identified gaps and limitations of the reviewed studies are discussed. Chapter two concludes with a discussion of the relevant recommendations linked to the reviewed literature.

2.2 Literature review justification

Traditionally, when undertaking quantitative and most qualitative research, a literature review is required prior to data collection to establish the need for and to guide the development of the study. However, in grounded theory research there are alternative perspectives as to when the literature review should be conducted (Charmaz 2006; Wuest 2007; Birks & Mills 2011;Thornberg 2102; Charmaz 2014). Classical grounded theory suggests the literature review should not be undertaken until all the data has been collected and analysis has been commenced in order to not jeopardise the researcher's ability to analyse the data in a non-biased manner (Glaser & Strauss 1967; Thornberg 2012). However, Glaser and Strauss (1967) contradicted themselves by suggesting that researchers need to have theoretical sensitivity in order to formulate a theory from the data, which suggests researchers do in fact need to be aware of existing literature in their area of research. Furthermore, they suggested a researcher can use documents to assist in the formation of a hypothesis in the early phases of their study (Glaser & Strauss 1967). However, the use of the wording 'forming a hypothesis' contradicts the abductive nature of theory development in grounded theory (Reichertz 2007) and is more suited to the deductive method to ‘prove’ or ‘disprove’ a hypothesis in quantitative studies. Reichertz suggests abduction is a cerebral process that links things together, which may not have been previously associated with one another; ‘a cognitive logic of discovery’ (2007, p. 220). Overall, while Glaser and Strauss (1967) did not recommend a literature review pre data collection and analysis, they were not opposed to researchers developing a hypothesis from the literature or needing to be theoretically sensitive to the data collected, which indicates researchers can have some prior knowledge of their area of study.

Following the separation of the union of Glaser and Strauss, Glaser (1998) maintained his stance on the timing of the literature review. He insisted a literature review in the substantive or related area would impact on the researchers’ ability to have their codes emerge purely from their data and not from their reading of the literature (Glaser 1998). Glaser (1992) even suggested the literature is not reviewed until the generation of a core category. However, he also stated:

> ‘It is necessary for the grounded theorist to know many theoretical codes in order to be sensitive to rendering explicitly the subtleties of the relationship in his data’ (Glaser 1998, p. 72).

Glaser’s (1998) view indicates that researchers should not be familiar with the literature because it will jeopardise their ability to analyse the data. However, he then asserted that the researcher needs to be aware of the theoretical codes, which can only occur through the researcher being familiar with the literature (Charmaz 2006; Thornberg 2012).

Straussian grounded theory (Strauss & Corbin 1990; 1998) made a shift from the classical grounded theory view on the timing of the literature review. It acknowledged the fact that the researcher enters into research with ‘life experience and knowledge related to the literature’ (Strauss & Corbin 1990; Giles, King & de Lacey 2013, p. 31). It is therefore difficult to be completely removed from the literature in an area of interest once previous knowledge and experience are taken into consideration. The prior knowledge and experience of the researcher was seen by Strauss and Corbin (1998) to enhance theoretical sensitivity and theoretical sampling in grounded theory method. Similarly, Yarwood–Ross and Jack (2015) believe the use of the literature in Straussian grounded theory can direct theoretical sampling and assist in development of concepts. Overall, Strauss and Corbin's (1998; Corbin & Strauss 2008) position appeared to subscribe to opposing views; they believe being familiar with the literature can block creativity and conversely that the same familiarity can enhance the analysis of the data, especially subtle nuances in the data.

Charmaz (2006) acknowledged that researchers bring with them previous knowledge and experience to any research they conduct. In addition, Bryant and Charmaz (2007) suggested the use of the literature can provide a beginning framework for the study as well as orientation. Charmaz (2006) suggested a preliminary literature review be undertaken in CGT. However, she discourages novice researchers from undertaking an in-depth review in order to avoid becoming influenced by the literature when developing their categories and theories (Charmaz 2006). She recommends that once the researcher has begun their data analysis and developed categories, the preliminary literature review can then be taken into consideration (Charmaz 2006). Giles, King and de Lacey (2013, p. 38) suggested 'a preliminary literature review can enhance grounded theory research without defining it', as long as the literature is used reflexively.

During data generation and analysis Charmaz (2006, p. 166) suggested:

> 'completing a thorough, sharply focused literature review strengthens your argument and your credibility.'

Therefore, the option to conduct a preliminary review of the literature and then to follow up with a more extensive review of the literature during data generation and analysis was chosen for the study. Therefore, I am aligned with the preliminary literature review supported by Charmaz in the CGT methods (Charmaz 2006; 2014).

It must be acknowledged that I began the study with pre-existing knowledge and experience in the research area. I have previously conducted a study examining the experiences of people with T1D when admitted to hospital. Over the course of that study I inevitability became familiar with the related literature. In addition, my previous academic position included post graduate teaching in

Diabetes Management and Education and as a result, I interacted with numerous health professional colleagues who practice in the area of diabetes.

Due to my pre-existing knowledge and experience it was not possible to enter into this study without preconceived ideas. Bryant and Charmaz (2007) agreed it is not possible to start a study without prior knowledge of the area and the researcher must attempt to minimise any bias by employing reflexivity. Reflexivity is discussed further in Chapter four (see 4.9 on page 69).

Finally, there is recognition of the need for a preliminary literature review amongst grounded theorists despite the specific grounded theory method selected. Glaser (1998) recognised that in order for research to be financially supported, a research proposal is usually needed and requires a review of the literature. Charmaz (2006) and Wuest (2007) agreed with the idea of the preliminary literature review being required by research funding bodies or for a thesis committee to justify the need for a grounded theory study. Furthermore, ethics committees usually require information about the significance of the study to determine whether the study is ethically sound which, provides another reason to undertake a preliminary literature review (Birks & Mills 2011). The University's requirement for this PhD was a submission of a research proposal, which included the chosen methodology and ethics committee approval (prior to data generation), which required a review of the literature to be included.

2.3 Article search and selection

An initial search of relevant electronic databases focused on research published between 2005 and 2015 to ensure the retrieved studies were current. Articles were confined to those written in English because it is my first language and resources for translation were not available. The studies needed to be primary research specific to adults (18 years and older) who had experienced T1D self-management while they were in hospital for a primary admission diagnosis other than their diabetes. The electronic databases initially searched were the Cochrane database of Systematic Reviews, Scopus, PubMed, and CINAHL. Keywords used were type 1 diabetes mellitus, type 1 diabetes, Self-management or self-care, inpatient, hospital and adult (see Appendix 1 on page 243).

Due to a limited number of studies retrieved from the afore mentioned databases the inclusive publication dates were altered from 2005 to 2015 to 2000 to 2015 in an attempt to include more literature relevant to the topic. Studies were excluded if the focus was solely on type 2 diabetes (T2D), T1D in children younger than 18 years or T1D being the primary hospital admission diagnosis; Diabetic ketoacidosis (DKA) or hypoglycaemia. Studies were included if the focus was on T1D management, self-management, the perspective of the person with T1D or management of T1D management in hospital (see Appendix 2 on page 245).

2.4 Summary of the literature

There was scant literature related specifically to T1D self-management in hospital. The sole study focusing on this issue was conducted in a mid-Atlantic state of America in 1988 (Germain & Nemchik 1988). A small aspect of another study included patient outcomes for continuous subcutaneous insulin infusion (CSII) therapy in hospital (Noschese et al 2009). Data were collected by asking participants for their perspective on managing their CSII during their admission (Noschese et al 2009). In addition to these studies, two policy documents, one published in the United Kingdom and the other in the United States of America, advocate for diabetes self-management in hospital (see 1.4.4 on page 8). However, as previously discussed, these documents are predominately based on expert opinion, rather than primary research, therefore they were not included in the review. As a result of the scant literature available, the review included studies in which the management of T1D in hospital was not the sole focus but which had findings linked to the management of T1D in hospital.

The majority of the studies reviewed focused on managing diabetes in hospital from the health professionals' perspective. A number of other studies reviewed focused on the health professionals' knowledge of diabetes management in hospital. The overall lack of studies from the perspective of the person with T1D while they are in hospital substantiates the researchers' position that there is a deficit of knowledge in the area.

2.5 Methodological review

The 25 studies reviewed were all primary research; 21 were quantitative studies and four were qualitative studies. All studies were scrutinised using an appropriate critical appraisal tool specific to the research methodology. The qualitative studies were appraised using the Critical Appraisal Skills Program (CASP) tool to determine the rigour and credibility of the studies (CASP 2002). The Health Care Practice Research and Development Unit's (HCPRDU) evaluation tool for quantitative studies was used to determine the validity of the quantitative studies (HCPRDU) 2003).

2.5.1 Quantitative studies

The 21 quantitative studies reviewed mostly consisted of retrospective chart analyses, descriptive, and non-experimental designs. Retrospective chart analysis relies solely on health professionals' complete documentation in the clinical notes and as a result there is potential for some missing data, which can affect results. Limitations of the other quantitative studies included small sample size, sampling issues, use of non-validated tools, potential bias, non-recognition of confounders and limited statistical power, which affects the ability to generalise the results.. However, the studies were assessed as having sufficient rigour to include in the review using the HCPRDU tool and were relevant to the phenomenon being explored.

2.5.2 Qualitative studies

The four qualitative studies reviewed predominantly used grounded theory and one study used secondary analysis of qualitative data. Ethical weaknesses identified included limited or lack of discussion of ethics approval along with limited discussion about ethical issues in research such as informed consent, confidentiality and the possible impact of the study on participants. Weaknesses were also identified in relation to researcher bias where the authors did not acknowledge their own actual or potential bias or consider any alterations to the study in response to events that occurred during data collection. Despite the limitations identified through critical appraisal, the studies were deemed to have sufficient quality and relevance for inclusion in this review.

2.6 Presentation of the findings

The synthesised findings from the 25 analysed studies are presented thematically under three main headings. *Management of T1D in hospital*, which has a primary focus on the management of T1D by health professionals and includes one study that represents the patients' perspective of self-management of T1D in hospital. *Health professionals' knowledge of diabetes,* which focuses on studies that have examined health professionals' knowledge of managing diabetes in hospital. *The expert patient*, which focuses on the development of the expertise of people living with a chronic condition, including participants with T1D (see Appendix 3 on page 246).

2.6.1 Management of T1D in hospital

People with T1D are admitted to hospital for a variety of reasons. Only one study that included self-management of T1D in hospital was identified. The remainder of reviewed studies in this section focused on health professional management of diabetes in hospital and the use of continuous subcutaneous insulin infusion (CSII) in hospital.

2.6.1.1 Self-management of T1D in hospital

A study by Germain and Nemchik (1988) directly relates to the phenomenon of self-management of adults with T1D in hospital. While it was published outside of the inclusion criteria dates, the study's findings are particularly relevant for the study, hence it was included. Germain and Nemchik (1988) used a descriptive survey to ascertain individual's desires, concerns and experiences relating to retaining self-management of their T1D prior to and whilst in hospital. The study found 79% of participants (n=73) with T1D supported the continuation of self-management in hospital, while 8% would reluctantly accept assistance if required (Germain & Nemchik 1988). Despite this finding, Germain and Nemchik (1988) discovered diabetes care in hospital was predominately carried out by the health professionals.

Ninety two percent of participants expressed concern regarding their diabetes care during future episodes of hospitalisation, including the monitoring and treatment of their T1D, as a direct result of their hospital experiences. Perceived competence and knowledge levels of health professionals by the participants left them feeling insecure about their diabetes management (Germain & Nemchik

1988). Additionally, the fear of hypoglycaemia and limited food access were specific concerns of some participants, leaving them feeling powerless to control their diabetes in hospital (Germain & Nemchik 1988).

Germain and Nemchik (1988) concluded that patients with T1D in hospital wanted to feel confident that they would be provided with competent care if they are unable to care for themselves. In order for the patients to feel confident in the health professional's ability to provide competent care, Germain and Nemchik (1988) suggested health professionals require continuous education in T1D management. The researchers also recognised diabetes self-management appears to be unidirectional as initially individuals learn self-management in hospital then are discharged to the community. However, the developed self-manager is not automatically accepted back in the hospital environment as capable of self-managing their own T1D (Germain & Nemchik 1988).

However, the study has some recognised limitations including its use of a descriptive survey, its small sample size (n=73) and the non-random nature of recruitment. In addition, there is no discussion about how the data generated from the open ended questions were analysed. Moreover, the study is over 30 years old and does not provide an in-depth understanding of people's experience of T1D self-management in hospital.

2.6.1.2 T1D management in hospital

While there is limited published research on self-management of T1D in hospital, a number of quantitative studies (descriptive and observational) examined health professionals' management of patients with diabetes in hospital. Health professional management also includes the use of CSII in hospital. The studies that focused on the health professionals' use of CSII in hospital predominately used retrospective chart analysis.

2.6.1.2.1 Timing of inpatient diabetes management

In a descriptive, non - experimental study, Cohen et al (2007) found morning diabetes management, in a selected hospital, was not conducted well. Examples of factors that influenced morning diabetes management included breakfast tray delivery times and nurses' shift times, which impacted on the timing of blood glucose monitoring (BGM) and insulin administration (Cohen et al 2007). Furthermore, the time lapse between BGM and insulin administration led to incorrect doses of insulin being administered in relation to actual insulin requirements. For example, Cohen et al (2007) found 72% of the insulin doses were administered outside the expected timeframe for short acting insulin administration with approximately 33% of doses being administered one and a half hours prior to breakfast instead of the recommended half an hour. These timing issues were found to increase risk of pre-lunch hyperglycaemia by five times (Cohen et al 2007). Additionally, inconsistent medical treatment orders around insulin administration and blood glucose monitoring (BGM) impacted on patients' diabetes management (Cohen et al 2007).

Lampe et al (2014) undertook an observational study around mealtime insulin practices in four cardiology units in two hospitals. The focus of their observation data was timing of meal tray delivery, first bite of the meal by the patient and the time the nurse administered the rapid acting insulin to the patient (Lampe et al 2014). The study found only 14% of patients (n=64) had their BGM and insulin administered within the study's established timeframe; BGM <60 minutes prior to insulin administration and insulin administered 15 minutes prior to the first bite of the meal (Lampe et al 2014). The identification of varied practices and asynchronicity of BGM, insulin administration and meal delivery demonstrated patients requiring rapid acting insulin were not receiving ideal care within specified time frames, which can lead to hypoglycaemia and affect glycaemic control.

2.6.1.2.2 Inpatient hypoglycaemia management

Anthony (2007) in the United States of America, and Coats and Marshall (2013) in New Zealand, conducted retrospective chart analysis on the treatment of hypoglycaemia in adult inpatients in medical and surgical ward settings. Both studies examined documented evidence of adherence to each hospital's hypoglycaemia protocols; a five step protocol (Anthony 2007) and an eight step protocol (Coats & Marshall 2013). While the focus of these studies was not specific to those with T1D, patients with T1D were represented in their sample in a similar proportion to the proportion of T1D in overall worldwide population; 10%, with the remainder of participants having T2D.

The findings from both studies showed health professionals' adherence to hypoglycaemia treatment protocols was low. Anthony (2007) found that out of 484 documented episodes of hypoglycaemia in two hospitals, not one episode showed adherence to the five-step hypoglycaemia policy. Similarly Coats and Marshall (2013) found overall adherence to the eight step hypoglycaemia hospital policy was 'low' in 117 audited episodes of hypoglycaemia. However, there are limitations to relying on audited documents because they are based on nursing staff correctly documenting treatment against the recommended protocol and there may be missing or inaccurately recorded data (Anthony 2007; Coats & Marshall 2013). While both studies focused on health professionals' management of inpatients' hypoglycaemia, their recommendation focused on the need for the health professionals to improve. In these studies there was no consideration of the patient's ability to manage, or be involved in managing their hypoglycaemia while hospitalised.

2.6.1.2.2 CSII use in hospital

There has been an increase in the use of CSII for people managing their diabetes in most developed countries since its introduction in the 1980s (Noschese et al 2009). As a result, health professionals are more likely to encounter patients with T1D using their own CSII in hospital (Bailon et al 2009; Noschese et al 2009; Nassar et al 2010). A number of quantitative studies examined the use of CSII in inpatients using retrospective chart analysis with the majority focusing on health professionals' management of CSII.

2.6.1.2.3 Glycaemic control with CSII use in hospital

The reviewed studies indicate a variation of results on whether glycaemic control can be achieved using CSII in hospital (Leonhardi et al 2008; Bailon et al 2009; Noschese et al 2009; Nassar et al 2010; Cook et al 2012). These studies used documented data from patients' charts, which recorded episodes of hypoglycaemia, hyperglycaemia and blood glucose levels to examine the control of BGLs in hospital using CSII.

Two studies, (Bailon et al 2009; Cook et al 2012), found there were less recorded episodes of hypoglycaemia amongst patients using CSII in hospital compared to those patients who had their pumps removed during hospitalisation for either the entire episode of care (Bailon et al 2009) or for part of their episode of care (Cook et al 2012). Bailon et al (2009) and Cook et al (2012) found statistically significant reductions in the number of hypoglycaemia episodes amongst the participants wearing their CSII compared to those in the group without their CSII. In relation to hyperglycaemia, Bailon et al (2009) did not find a significant reduction between their comparison groups; CSII on versus CSII off, while Cook et al (2012) suggested there were significantly fewer episodes of hyperglycaemia among the CSII users.

Leonhardi et al (2008), Noschese et al (2009) and Nassar et al (2010) were not as conclusive in their findings related to glycaemic control amongst CSII use in hospital. Nassar et al (2010) could not find any significant difference in documented hyperglycaemia, hypoglycaemia or average blood glucose levels between CSII on, CSII off or intermittent CSII groups. Noschese et al (2009) found no significant difference between glycaemic control and episodes of hypoglycaemia in their participants. They did however find episodes of hyperglycaemia were higher among CSII users who were not using the hospital’s specific inpatient insulin pump protocol, or had not received an inpatient diabetes service consultation (Noschese et al 2009). Leonhardi et al (2008) found those that were admitted using CSII had frequent documented episodes of hypoglycaemia and hyperglycaemia. However, they did not have a comparison group like the other reviewed studies (Bailon et al 2009; Noschese et al 2009; Nassar et al 2010; Cook et al 2012). In addition, Leonhardi et al’s (2008) sample size for this study was too small (n=21) to enable the findings be generalised.

2.6.1.2.4 Adverse events with CSII use in hospital

Adverse events related to the use of CSII in hospital were reported in three studies from retrospective chart analysis (Noschese et al 2009; Nassar et al 2010; Cook et al 2012). Adverse events such as diabetic ketoacidosis due to hyperglycaemia or the effects of hypoglycaemia, can be caused by mechanical pump malfunction, infection at the catheter insertion site, kinking of the infusion catheter or tubing leaking (Noschese et al 2009; Cook et al 2012).

The reviewed studies found there were limited adverse events related to the use of CSII in hospital (Noschese et al 2009; Nassar et al 2010; Cook et al 2012). Nasser et al (2010) and Cook et al (2012) both reported on the same adverse episode, from 83 patients, which resulted from the CSII tubing kinking, which led to nonfatal hyperglycaemia. Noschese et al (2009) reviewed 50 inpatient medical records and found one episode of pump malfunction and an infusion site problem documented. These findings suggest that the use of CSII in hospital is not likely to lead to significant adverse events, likely to impact the patient.

2.6.1.2.5 Health professionals and patients perspective towards inpatient CSII use

Noschese et al (2009) suggested outpatients who use CSII can be considered for self-management of their diabetes in hospital if they have the mental and physical capacity to manage. However, health professionals are reported to feel uncomfortable allowing inpatients to self-manage their CSII due to the health professionals' lack of knowledge and lack of familiarity with the CSII (Noschese et al 2009). One study explored the patients' experience of CSII management in hospital (Noschese et al 2009) while two studies explored the health professionals' familiarity with CSII management in hospital (Cook et al 2007, Cook et al 2008).

2.6.1.2.6 Patient satisfaction of CSII use in hospital

One study reported patient satisfaction in relation to CSII use in hospital. Noschese et al (2009) conducted a patient satisfaction survey with 17 of their 50 participants who were monitored by an inpatient diabetes service. The majority of patients (>80%) were satisfied with their CSII management in hospital and felt the hospital staff supported their CSII use. These patients also agreed that the health professional recommended adjustments to their CSII rates were appropriate for maintaining BGLs in hospital (Noschese et al 2009). However, approximately half of the 17 patients felt they were not in control of their diabetes management in hospital despite the continuation of their CSII (Noschese et al 2009). There was no further explanation offered in the study as to why the patients felt they did not have control of their diabetes. However, the study mentioned that most patients were required to follow the hospital's CSII protocol rather than their usual self-management preferences.

2.6.1.2.7 Health care providers' familiarity with CSII use in hospital

Cook et al (2007) and Cook et al (2008) explored the familiarity of resident physicians and mid level practitioners (physician assistants and nurse practitioners) with managing inpatient hyperglyaemia. Both studies used a version of the Mayo clinic inpatinet diabetes management survey to collect data; verison 1 for Cook et al (2007) and version 2 for Cook et al (2008). For those participants in Cook et al's (2008, p. 78) study, 86% (n=51) identified they were 'not at all comfortable' using insulin pumps.

Both of the inpatient settings in Phoenix, Arizona, had existing CSII policies and CSII orders. Cook et al (2007, p. 119) found 58% of participants (n=52) were 'somewhat familiar' with the CSII policy and 40% were 'not at all familiar'. In relation to the institutions CSII order 54% were 'somewhat familiar' and 44% were 'not at all familiar' (Cook et al 2007, p. 119). Only 2% of resident physicians identified themselves as being 'very familiar' with both the CSII policy and CSII order (Cook et al 2007, p. 119). Among the mid level practitioners (n=51), 22% identified themselves as 'somewhat familiar' with both the CSII order and CSII policy, 68% identified as 'not at all familiar' with the CSII policy while 72% recognised they were 'not at all familiar' with the CSII order (Cook et al 2008, p. 78). Cook et al (2008, p. 78) also found some staff (8%) were unaware that a CSII policy existed in their institution and 6% were unaware of the availability of CSII orders. These studies suggest that a range of health professionals were not familiar with CSII in the inpatient setting despite there being policies and orders in place to support them (Cook et al 2007; Cook et al 2008).

2.7 Health professionals' knowledge of diabetes

Based on the growing prevalence of diabetes as a co-morbid condition of inpatients, health professionals[2] should have sufficient knowledge about diabetes management (Cook et al 2007; Cook et al 2008). A number of the studies reviewed suggest that health professionals do not have sufficient understanding of diabetes management, which can impact on the care they provide. However, health professionals need to have knowledge of diabetes management for inpatients,

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[2] Health professionals in the reviewed studies were generalist health professionals and were not identified as having diabetes expertise

regardless of the discipline they work in because diabetes can complicate the person’s admission diagnosis (van Zyl & Rheeder 2008).

2.7.1 General diabetes knowledge

A variety of validated tools were used in these studies to evaluate health professionals’ diabetes knowledge and assessed perceived knowledge, actual knowledge and attitudes towards patients with diabetes. These tools included the Diabetes Basic Knowledge Tool (DBKT) (Gerard, Griffen & Fitzpatrick 2010) and its modified version (MDBKT) (Yacoub et al 2014), Diabetes Self-Report Tool (DSRT) (Gerard, Griffen & Fitzpatrick 2010; Yacoub et al 2014), Diabetes Attitude Questionnaire (DAS3) (van Zyl & Rheeder 2008) and the Diabetes Management Knowledge Assessment Tool (DMKAT) (Modic et al 2014). While these tools are not specific to T1 or T2D, they do include a variety of questions that are relevant to the knowledge required by health professionals when managing T1D in hospital. For example, the DBKT includes questions about managing of insulin, hypoglycaemia management, BGM and meal planning (Gerard, Griffin & Fitzpatrick 2010).

Gerard, Griffin and Fitzpatrick (2010) described nurses’ (n=93) general knowledge about diabetes as ‘mediocre’ by examining scores collected through the DBKT and DSRT. The perceived knowledge level of the participants using the DSRT demonstrated nurses perceived their knowledge to be a mean score of 60 out of 80 (Gerard, Griffin & Fitzpatrick 2010). The researcher’s described the mean score of 60 out of 80 as favourable and to be ‘equivalent to a “3” on the 1 to 4 Likert scale’ (Gerard, Griffin & Fitzpatrick 2010, p. 163). The nurses’ actual knowledge, using the DBKT, showed they achieved a mean score of 68% correct responses. Gerard, Griffin and Fitzpatrick (2010) found significant differences in nurses’ knowledge across the diabetes concepts in the DBKT. Overall, they found no significant relationship between the perceived and actual knowledge of the nurses (Gerard, Griffin & Fitzpatrick 2010. In addition, Modic et al (2014) and Trepp at al (2010) found that nurses reported a high level of comfort providing care to patients with diabetes despite their low levels of knowledge, which could suggest nurses overestimate their knowledge in diabetes care.

van Zyl and Rheeder (2008) used the DAS3 and the Diabetes Knowledge Questionnaire (O'Brein, Michaels & Hardy 2003) to examine the attitudes and knowledge of general nurses (n=61) and general medical staff (n=54) about diabetes inpatients. They found doctors had poor knowledge about diabetes treatment, insulin administration and dietary management (van Zyl & Rheeder 2008). Overall, limited knowledge among health professionals regarding diabetes management for the inpatient with any type of diabetes was identified. However, the health professionals recognised their need for further diabetes related training in this area (van Zyl & Rheeder 2008).

Specific to diabetes education Gerard, Griffin & Fitzpatrick (2010) found half of their 93 participants had not undertaken any diabetes education in the previous two years. Modic et al (2014) found nurses had a lower level of knowledge about diabetes management for the inpatient in their pre-test, which did not relate to years of experience or education level. Following a four hour diabetes management course the post-test results showed an overall increase in diabetes management knowledge except for questions related to insulin regimes and the causes of hyperglycaemia (Modic et al 2014). However, Modic et al (2014) recognised the post-test results may be skewed because the nurses were familiar with the questions from pre-test.

2.7.2 Insulin knowledge

A number of studies used a variety of tools to evaluate knowledge of health professionals concerning insulin management in hospital. The majority of these studies found there were self-reported knowledge deficits related to safe insulin administration, including onset of and duration of insulin action, prescriptions, preparation and administration (Cook et al 2007; Gerard, Griffin & Fitzpatrick 2010; Ahmed et al 2012; Lee et al 2013; Modic et al 2014; Yacoub et al 2014).

Lee et al (2013) used a questionnaire and found health professionals had a significant knowledge gap about the use of insulin, despite indicating they felt 'very' or 'somewhat' comfortable in managing diabetes. While the questionnaire used in this study was reviewed by endocrinologists it was not a validated tool, which could impact on the interpretation of the questions by the health professionals. Lee et al (2013) acknowledged the non-validated tool as a limitation of their study. Similarly Cook et al (2007) and Cook et al (2008) also used a non-validated questionnaire, and found their resident physician and mid-level provider participants reported that knowing what type of insulin or which regime worked best was their biggest barrier to managing inpatient hyperglycaemia.

Gerard, Griffin and Fitzpatrick (2010) used the DBKT and found less than 50% of nurses (n=93) were knowledgeable about onset time of insulin, 34% had some knowledge about correct storage of insulin and only 14% knew what the initial treatment was for hypoglycaemia. Within the same cohort of nurses 99% reported they knew the effects of insulin, 98% reported they could identify correct injection technique and 94% knew peak time of insulin action (Gerard, Griffin and Fitzpatrick 2010). Overall this study found nurses had a ‘mediocre’ actual knowledge of diabetes management (Gerard, Griffin & Fitzpatrick 2010, p. 164).

Ahmed et al (2012) found that 38% of the health professionals (n=381) they surveyed were familiar with the duration and action of various insulins. Within the cohort of health professionals 99 were registered nurses (RN) (n=99/381) and within the RN cohort only 2% identified as being familiar with the duration and action of various insulins. Approximately a third of the registered nurse participants had suboptimal knowledge of insulin and other glucose lowering medications (Ahmed et al 2012). Modic et al found the nurses in their study had difficulty answering questions in both the pre and post-test to those questions that related to insulin ‘pharmacokinetics and efficacy of different insulin regimes’ (2014, p. 159). Yacoub et al (2014) used both the DSRT and MDBKT and found nurses lacked understanding of insulin (preparation, storage, injection sites), which demonstrated a deficit in pharmacology knowledge. Yacoub et al’s (2014) study also found less than 50% of its 277 participants knew the symptoms of hypoglycaemia, which is an issue when administering insulin because it means they may not understand the most significant side effect which could delay early hypoglycaemia treatment (Yacoub et al 2014).

2.7.3 Dietary requirements

Four quantitative studies examined knowledge of dietary requirements of people with diabetes in hospital (Gerard, Griffin & Fitzpatrick 2010; Park et al 2011; Oyetunde & Famakinwa 2014; Yacoub et al 2014). Gerard, Griffin and Fitzpatrick (2010) found less than 50% of nurses (n=93) were knowledgeable about meal planning for those living with diabetes. Oyetunde and Famakinwa (2014) also found knowledge about nutrition for diabetes management was low with only 29.2% of their 401 participants achieving a score of 70% and higher, which was determined as the pass mark, leaving 79.8% demonstrating poor knowledge of general nutrition.

Park et al (2011) used a dietary knowledge questionnaire with 8 of the 42 questions being specific to diabetes. The average correct response rate to the diabetes specific questions was 68% (Park et al 2011). However, 70% of the 506 nurses did not know that complex carbohydrates did not require restriction for the patient with diabetes, while 96% recognised simple carbohydrates required restriction (Park et al 2011).

2.7.4 Blood glucose monitoring

Yacoub et al (2014) identified poor knowledge of blood glucose monitoring among 277 nurses (45% correct) and poor understanding of BGM accuracy (36.8%). Cook et al (2007, p. 119) found resident physicians did not feel ‘good glucose control’ was ‘very important’ for patients outside critical care or perioperative areas, which represented a knowledge deficit. This finding may also indicate a possible attitude towards the importance of diabetes management in hospital outside the critical care area.

Overall it can be concluded from the studies reviewed that international health professionals, in particular nurses, have knowledge deficits about most aspects of diabetes management in hospital. While all these quantitative studies focused on health professionals’ knowledge about diabetes, all the strategies suggested for improving the knowledge deficits focused on providing further education for health professionals. Notably collaboration with the patient with diabetes was not stated as a potential teaching strategy.

2.8 The expert patient

People living with a chronic condition, such as T1D, are known to develop expert knowledge of their body and how their body responds to illness (Paterson & Thorne 2000; Paterson & Thorne 2000a; Thorne, Paterson & Russell 2003; Kralik et al. 2004). Four of the qualitative studies reviewed recognised expert knowledge exists and included responses of health professionals to the patient’s expertise (Thorne, Ternulf Nyhlin & Paterson 2000; Paterson 2001; Henderson 2003; Wilson, Kendall and Brooks 2006). These studies suggested that people with chronic conditions have their expertise disputed or disregarded by health professionals, which can reinforce the existing power imbalance between people with T1D and the health professionals (Thorne, Ternulf Nyhlin & Paterson 2000; Paterson 2001; Henderson 2003; Wilson, Kendall and Brooks 2006).

2.8.1 Health professionals exert their expertise

Two studies found health professionals tend to exert their expertise over the expert patient (Thorne, Ternulf Nyhlin & Paterson 2000; Wilson, Kendall & Brooks 2006). Thorne, Ternulf Nyhlin and Paterson (2000) conducted a secondary analysis of two data sets from their previous research with people with T1D and people with Environmental Sensitivities (ES). They found health professionals tended to exert their expertise over both patient groups due to their professional values and attitudes. Specific to T1D, they found conflict often occurred between the patient with T1D and the health professional over prescribed insulin doses in hospital. This conflict occurred as a result of the health professional making assumptions that their interpretation of diabetes management is superior to that of the individual with T1D (Thorne, Ternulf Nyhlin & Paterson 2000).

Wilson, Kendall and Brooks (2006) further explored the concept of health professionals’ responses to the expert patient with a specific focus on nurses’. They used a grounded theory approach to explore how both patients and health professionals viewed, interpreted, experienced and defined patient expertise (Wilson, Kendall & Brooks 2006).[3] Wilson, Kendall and Brooks (2006) found nurses relied heavily on physical measurements, such as HbA1c, as a method for determining trustworthiness of patient’s with T1D self-management expertise. Similarly, Thorne, Ternulf Nyhlin and Paterson (2000) found health professionals tended to focus on rationalising response to illness through biomedical science, while patients viewed their chronic condition holistically. They concluded that the health professionals’ biomedical focus may lead to patients being labelled as

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[3] Patients with T1D were represented in the participant sample group, but were not the sole focus of this study (Wilson, Kendall & Brooks 2006).

‘non-compliant’ if they have modified their prescribed treatment regime (Thorne, Ternulf Nyhlin & Paterson 2000). Such labelling leads to health professionals questioning patients’ self-management decision-making ability and their level of expertise potentially disregarding their accumulated knowledge (Thorne, Ternulf Nyhlin & Paterson 2000). While health professionals may judge a person with T1Ds self-management ability by relying on numbers to assess glycaemic control, it is important to remember that numerous factors impact on a person’s capacity to achieve glycaemic control. However, judging the patient on the basis of objective data alone, rather than holistically, was a common theme across the reviewed qualitative studies (Thorne, Ternulf Nyhlin & Paterson 2000; Paterson 2001; Wilson, Kendall & Brooks 2006).

2.8.2 Nurse response to the expert patient

Wilson, Kendall and Brooks (2006) found that nurses claimed expert patients require more of their time because they actively seek information about their condition and attempt to engage in discussions on their treatments. Nurses described these behaviours as a hindrance to the development of a relationship with the expert patient and to the management of time for their nurse led clinics (Wilson, Kendall & Brooks 2006). In addition, nurses believed their relationship with the expert patient was further hindered because the nurse’s professional confidence and years of experience were being questioned and diminished by the expert patient’s knowledge (Wilson, Kendall & Brooks 2006). Nurses believed they should have authoritative knowledge over the patient however, some nurses implied that the adage of ‘nurse knows best’ no longer exists as a common perception amongst patients, particularly due to the internet increasing people’s ability to access their own health related information (Wilson, Kendall & Brooks 2006). As a result of patients’ increasing health literacy through access to information, they are no longer recognised as passive recipients of care who rely on the nurse (Wilson, Kendall & Brooks 2006).

As well as the expert patient being viewed by nurses as a hindrance to the nurse-patient relationship, Wilson, Kendall and Brooks (2006) concluded that nurses appeared to find the expert patient to be a threat. Feeling threatened may be attributed to the unclear role definition of nursing and the level of expertise of the nurse as a result of the medical dominance over the profession of nursing (Wilson, Kendall & Brooks 2006). As a professional group, nurses voiced concerns that advice they provided to expert patients may result in litigation. However, the fear of litigation was assumed, rather than an actual experience of the nurse (Wilson, Kendall & Brooks 2006).

Nurses also expressed they felt governed by workplace protocols that inhibited facilitation of self-management. As a result of workplace governance, nurses claimed they felt oppressed, and acknowledged they then directed their resentment towards the expert patient (Wilson, Kendall & Brooks 2006). These findings provide insight into nurses' perceptions of and responses to the expert patient that may impact on the acceptance and support for T1D self-management in hospital.

2.8.3 Recognising power imbalances

Two of the reviewed articles examined the power imbalances that exist between health professionals and the expert patient (Paterson 2001; Wilson, Kendall & Brooks 2006). While Henderson (2003) specifically explored strategies nurses used to exert their power over general patients. The studies reviewed suggested people with chronic conditions experience counterproductive attitudes from health professionals that influenced their ability to self-manage (Thorne, Ternulf Nyhlin & Paterson 2000; Henderson 2003; Wilson, Kendall and Brooks 2006).

Health professionals maintained their power by devaluing the experiential knowledge of the person with a chronic condition (Paterson 2001; Wilson, Kendall & Brooks 2006). One method health professionals use to devalue knowledge was to rely on measurable laboratory data such as BGLs (Paterson 2001; Wilson, Kendall & Brooks 2006). In addition, health professionals were reluctant to trust the patient with a chronic conditions' credible awareness of their body's response to their condition and emerging patterns (Paterson 2001). Paterson (2001) found such reluctance particularly occurred when the person's experience contradicted the textbook classification of the chronic condition (Paterson 2001). As a result, patient participants in Paterson's (2001) study felt health professionals were negating their actual needs because their focus was on compliance with prescribed care rather than the person's experience of self-managing their condition. In response to this feeling of being negated, Paterson (2001) found several participants admitted to lying about their self-management strategies because they had altered their prescribed management regime on the basis of self-knowledge and previous lived experience.

Another method health professionals used to maintain power was to limit access to the resources required by people with chronic conditions to participate in collaborative care and to make informed decisions (Paterson 2001). These resources included the method of information sharing along with time and monetary constraints, which impact on collaboration between the expert patient and the health professional. Participants claimed that when they had the opportunity to discuss their care, health professionals used medical jargon making it difficult for the participants to understand and participate in the discussion (Paterson 2001). In addition, health care interventions were made by health professionals without consideration of the participant's financial or social constraints (Paterson 2001). Consequently, ideal plans of care were determined by health professionals only, leading to participants feeling excluded from decision-making about their chronic condition management (Paterson 2001). Not treating the expert patient as an equal participant in their health care may be demeaning to the individual, does not consider their needs and further enforces the dominance of the biomedical model in health care.

Henderson's (2003) study further supported the phenomenon of a power imbalance between the health professional, in particular nurses, and the patient. Her grounded theory study found nurses preferred to make decisions for the patients rather than assisting patients to make their own decisions (Henderson 2003). As a result, the majority of nurses were reluctant to share decision-making powers with patients in regard to their patients' care (Henderson 2003). In addition, patients in Henderson's (2003) study reported nurses withheld information they needed in order to make informed decisions. Nurses withheld information by controlling interactions they had with patients by only asking closed ended questions, which limited their engagement with patients (Henderson 2003). Factors identified as strong influences on the nurses' behaviour included the patient's perceived lack of medical knowledge, the belief that the nurse 'knows best' and the idea that nurses need to hold onto their power and control (Henderson 2003).

Paterson's (2001) and Henderson's (2003) studies indicated a power imbalance exists between health professionals and expert patients. Overall, Paterson (2001) and Henderson (2003) found that health professionals suppressed the patient's decision-making ability in order to maintain control over the patient rather than attempting to work collaboratively. Another method of health professionals maintaining power over the expert patient was to devalue their experiential knowledge and only value medical knowledge (Thorne, Ternulf Nyhlin & Paterson 2000; Paterson 2001; Wilson, Kendall & Brooks 2006). The recognition in the reviewed literature of the existence of a power imbalance between the health professional and the patient could influence T1D self-management in hospital.

2.9 Discussion

The findings from the reviewed studies suggest that overall management of diabetes in hospital is poor, health professionals' knowledge and competence to manage the patient with T1D requires improvement and there needs to be further acceptance of the knowledge and competence of expert patient by health professionals. T1D management in hospital is recognised as problematic mainly due to the limited knowledge of health professionals about the chronic condition and its management (van Zyl & Rheeder 2008; Mabrey & Setji 2015). Cohen et al. (2007) and Anthony (2007) both concluded health professionals management of the patient with T1D in hospital is flawed and needs improvement. Contributing to flawed management in hospital is the timing of BGLs, meal delivery and insulin administration, which impact on diabetes management (Anthony 2007; Cohen et al 2007; Mabrey & Setji 2015). Furthermore, Anthony (2007) and Cohen et al (2007) suggested the focus of care is on the patient's primary admission diagnosis and not their diabetes, which contributes to diabetes being poorly managed in hospital.

The studies on hospital management of diabetes in the review were conducted in specific wards and were not hospital wide or multiple site explorations, thus the findings may not be generalised. A number of these studies are retrospective chart analyses, which show only documented information from the hospital and whether these practices meet their hospital or health professional needs in relation to T1D management. While the literature identifies there are issues for health professionals about managing T1D in hospital, the individual with T1D is not being recognised as a resource for improving T1D management in hospital and is an issue that should be explored in further studies.

However, what these studies do show is the majority were conducted by health professionals for their management of T1D yet the person with T1D has not been considered as the consumer of the health care or as a resource to be involved in their own care. None of the reviewed studies considered whether the patients with T1D have their needs met in relation to the management of their diabetes within hospital. However, all of the reviewed studies in sections 2.6 and 2.7 (see pages 20 & 26) fall short in recognising the individual with T1D as a resource for managing their chronic condition when hospitalised. The lack of recognition suggests that peoples’ perspective on inpatient management of their T1D needs further exploration and reporting.

A study by Houck, Tirumalasetty and Meadows (2013) examined patient satisfaction following an education intervention of health professionals about insulin administration and meal delivery coordination. They concluded it is important to educate patients and their families in hospital but only in relation to informing the nursing staff that their meal tray had arrived, if they are waiting for their BGL to be monitored, or that they need their insulin administered prior to eating (Houck, Tirumalasetty & Meadows 2013). Once again the focus is not on health professionals involving the patients in their care or enabling self-management, it is just involving the patients so the nurse can perform a task.

Gibson and Korytkowski (2014) suggested that patients managing insulin, which is labelled as a high-risk medicine (ACSQHC 2016), in the unfamiliar hospital environment while experiencing an episode of being acutely unwell could be problematic. However, what these reviewed studies demonstrate is that health professionals have a knowledge deficit in relation to insulin preparation, insulin administration and hypoglycaemia management (Cook et al 2007; Gerard, Griffin & Fitzpatrick 2010; Ahmed et al 2012; Lee et al 2013; Modic et al 2014: Yacoub et al 2014). Poor health professional knowledge on managing diabetes and insulin therapy can contribute to insulin errors as well as preventable hyperglycaemia and hypoglycaemia for patients (Smith et al 2005; Maynard et al 2008; Fowler & Rayman 2010; Abduelkarem & El-Shareif 2013). The identified knowledge deficit suggests that health professional management of insulin could be more harmful to the person with T1D in hospital than the expert patient self-managing their insulin.

In relation to insulin administration in hospital, some studies on CSII management provided some support for using CSII in hospital. While the findings seemed supportive of CSII continuation in hospital, the reliance on medical records as a data collection method can lead to inaccurate results because some data may be missing. Noschese et al (2009) and Shah and Rushakoff (2015) identified inpatients with T1D who use CSII were identified by health professionals as problematic to manage in the hospital environment because they are not familiar with CSII. However, the reviewed studies found some support in the literature for patients using CSII as an outpatient, to continue CSII use as an inpatient if there are standardised protocols in place. Cook et al (2012) even suggested successful policy implementation of inpatient pump therapy can be achieved with positive results for the patient. Once again, the person who is the inpatient with the pump was not considered or included in the process of making decisions around managing their pump in hospital. The perspective of the person with T1D and their experiences of CSII and diabetes management in hospital needs recognition because consumers' experiences and views are seen as significant in informing service delivery (Perry et al 2011).

The qualitative studies reviewed recognised the issues the expert patient faced in relation to attitudes held by health professionals. The attitudes of the health professionals predominantly arose from their need to maintain power over the expert patient. While these qualitative studies were all published over 12 years ago it was interesting to explore the current experience of the expert patient in hospital in this current study, in particular the acceptance or non-acceptance of their self-management. Therefore, exploring the experiences of the person with T1D in hospital can provide insight into the self-management requirements of the expert patient in hospital

A gap in the literature concerning the person's experience of managing their own diabetes in hospital exists because no one has previously explored the experiences of people living with T1D in hospital with a primary admission diagnosis other than T1D. Furthermore, no studies were found that generate a theory about the experience of self-management of people with T1D in hospital Therefore the current study aimed to address these gaps in knowledge.

2.10 Chapter summary

Chapter two explained and justified the inclusion of a preliminary literature review for the grounded theory study. The literature review included a critique of the reviewed studies and a discussion about the content of the reviewed studies around management of T1D in hospital. The chapter highlighted the identified limitations of the reviewed studies in the area of management of T1D in hospital and identified the current knowledge gaps. The preliminary review of the literature revealed there is limited current research available about the person with T1D self-managing in hospital however, the literature did reveal the management of T1D in hospital is poor largely because the health professionals' inadequate knowledge of T1D management. As a result of the identified knowledge gaps and limitations from the review, the aim of the study was determined, this being to explore of the experience of T1D self-management for adults in hospital. Chapter three describes the underlying epistemology, the theoretical underpinning and method used to meet the aims of the study.

Chapter Three: Methodology

3.1 Chapter overview

The aim of the study was to explore the experience of self-management of adults with type 1 diabetes (T1D) in Australian hospitals. The literature reviewed in Chapter two identified the majority of studies focusing on diabetes management in hospital are from the perspective of the health professional, predominately use quantitative methodologies and indicate that overall, in hospital diabetes is poorly managed. In addition, the literature suggests health professionals have varied understandings of diabetes management, which in some instances were shown to be inadequate. The reviewed literature on diabetes management in hospital does not consider the self-management expertise of people living with T1D and their capacity to contribute to improving T1D management in hospital. As there is minimal published research available on the person's experience of T1D self-management in hospital this current study set out to address the knowledge gaps and limitations identified in the reviewed literature.

Chapter three details the theoretical underpinnings and grounded theory methods used to construct a theory explaining the experience of T1D self-management in hospital. The chapter includes a discussion of the underlying epistemology of social constructionism as well as the relevance of the theoretical underpinning of symbolic interactionism in order to explore T1D self-management in hospital. In addition, the chapter includes an explanation for the decision to use a grounded theory method to meet the purpose and aim of the research and justifies the use of Charmaz's constructivist grounded theory (CGT) method to construct the substantive grounded theory.

3.2 Epistemology

Glaser (2004) dismissed the requirements of a philosophical underpinning for classical grounded theory method. He suggested instead that classical grounded theory method used an 'integrated conceptual hypothesis' in order to develop an inductive theory (Glaser 2004). Strauss (1987), and then Corbin and Strauss (2008), acknowledged both philosophical and sociological perspectives; symbolic interactionism, do underpin evolved grounded theory. Charmaz (2014) specifically acknowledges the underlying philosophical underpinning of CGT method as social constructionism. Therefore, social constructionism was the underlying epistemology of the study.

3.2.1 Social constructionism and constructivism

Social constructionism is embedded in the interpretive paradigm (Crotty 1998). The interpretive paradigm is interested in how people perceive and experience their social world and how they then construct meaning within their lives based on these perceptions and experiences (Charmaz 2014; Carminati 2018).

The term social constructionism is often substituted in the literature with social constructivism however there are recognised differences between the two terms (Crotty 1998; Burr 2003; Burr 2015). Social constructionism refers to the development of phenomena relative to social contexts while social constructivism refers to an individual making meaning within a social context (Vygotsky 1978; Crotty 1998; Burr 2003; Burr 2015). For this reason, social constructionism has been described as a sociological concept and social constructivism is viewed as a psychological concept (Burr 2015).

Social constructionism is centred on the idea that all knowledge and consequent meaningful reality:

> 'is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context' (Crotty 1998, p. 32).

Burr (2003) suggested that most of our life experiences as individuals are socially constructed with language being central to this process. The interactions between people in their daily lives are viewed by the social constructionist as pivotal to the way they construct knowledge (Burr 2015).

The social constructionist view of context helps us understand how 'behavioural interactions and orders are decided upon and are sustained within it' (Carroll 2008, pp. 80 – 81). Social constructionism, therefore is the observance of behaviours over time, which influence people's acceptance in social contexts of 'this is how things are' and 'this is the way things are done' (Carroll 2008, p. 80). As stated by Burr (2003, p. 45):

> '….a lot of things we take for granted as given, fixed and immutable, whether in ourselves or in the phenomena we experience, can upon inspection be found to be socially derived and socially maintained.'

Furthermore, Crotty (1998) suggested societies inherit meanings that shape people's interpretations and experiences within society and these meanings can remain influential throughout future generations.

According to Charmaz (2008) there are some assumptions that underlie her constructionist approach. These assumptions are:

1. 'Reality is multiple, processual, and constructed – but constructed under particular conditions';
2. 'The research process emerges from interaction';
3. 'It takes into account the researcher's positionality, as well as that of the research participants';
4. 'The researcher and participants' co construct the data; the data is a product of the research process….' (Charmaz 2008, p. 402).

In addition, constructionist researchers acknowledge the views and voices of their participants as being integral to the data analysis, rather than focusing only on the researcher's own points of view (Charmaz 2008).

3.2.2 Constructionist or *constructivist* grounded theory?

There is some confusion within the literature about the use of the term *constructivist* grounded theory as opposed to constructionist grounded theory. Charmaz (2014a) explained her decision for her initial shift from the label constructionism to *constructivism* in a 2014 Grounded Theory Master Class in Melbourne and further explored the concept in her 2014 *Constructing Grounded Theory* text. Initially Charmaz (2008) stated that her shift from constructionism to *constructivism* allowed her to distinguish her grounded theory method from the objectivist iterations of constructionist grounded theory method. Charmaz (2014) acknowledged she was dissatisfied with the way sociologists were conducting social constructionist research in the 1980s and early 1990s. Her view was that while sociology researchers 'produced impressive analyses of the construction of the worlds they studied' (Charmaz 2014, p. 14) they did not acknowledge their own subjectivity in the construction and interpretation of data or the influence of structural and situational encroachments. Therefore, Charmaz chose the term *constructivist* grounded theory to distinguish between her approach to grounded theory method and the traditional constructionist grounded theory method. However, Charmaz acknowledged social constructionism has evolved since the time of her dissatisfaction and she supports social constructionism within, what she continues to call, *constructivist* grounded theory method (Charmaz 2014). Therefore, the term social constructionism is used throughout the thesis.

3.2.3 Social constructionism and grounded theory method

Grounded theory method enables researchers to understand their participants' social construction of a phenomenon while also enabling researchers to construct the method through inquiry via their interactions with the research setting, their data, colleagues and themselves (Charmaz 2008). Charmaz (2008, p. 398) stated:

> 'The close attention that social constructionist grounded theorist give their research problems builds the foundations for the generic statements that they qualify according to particular temporal, social and situational conditions.'

Within grounded theory method 'a social constructionist approach' enables researchers to not only address the what and how questions, but also 'the why questions while preserving the complexity of social life' (Charmaz 2008, p. 397). Charmaz (2008, p. 398) recognised that, while classical grounded theory method provides a structure, within which research can be conducted, only the social constructionist researcher using grounded theory method develops innovative research that can 'develop new understandings and theoretical perspectives'

Charmaz (2008, p.398) advocates for a constructionist approach to grounded theory that first examines 'the relativity of the researchers' perspectives, positions, practices and research situation', second the researcher's reflexivity and finally the 'depictions of social constructions in the studied world'. The relativity and reflexivity of the constructionist approach enables researchers to critique their research process as they analyse the way their participants construct their realities (Charmaz 2006; 2008).

Charmaz (2008, p. 403) implied there were particular principles underlying current ‘social constructionist grounded theory’. These principles are:

1. Treating ‘the research process itself as a social construction’ rather than just following a recipe for qualitative research
2. Scrutinising ‘research decisions and directions’ where the researcher continually thinks about what they are doing and the how and why of what they are doing and being reflexive
3. Improvising ‘methodological and analytical strategies throughout the research process’
4. Collecting ‘sufficient data to discern and document how research participants construct their lives and worlds’ and the researcher being aware of their participants’ world view (Charmaz 2008, p. 403).

Therefore, the use of social constructionism as the underlying philosophical approach in the CGT study provides an understanding of the participants’ reality as they experienced it internally, how that experience is socially constructed and how they interpret their experience. In addition to social constructionism as the underlying epistemology in grounded theory method, the study also considered the influence of social constructionism on health and illness. Specifically the social construction of the experience of the person living with a chronic condition was considered. As stated by Martin & Peterson (2009, p. 579):

> ‘For those who experience the treatment for chronic disease, i.e. patients or consumers of health care, the process of constructing the experience and assigning meanings is highly personal and dependent on the social and other contexts in which they find themselves.’

Health and illness are socially created and are sustained by practices that serve the interests of dominant groups in society (Burr 2003; Burr 2015). Burr (2003, p. 40) stated:

> ‘The biomedical conceptualisation of health and illness is only one perspective among many, and its predominance in western societies cannot be understood as simply the result of progress in scientific knowledge. The rise of biomedicine can be seen to be at least in

> part related to changes in the exercise of social control taking over the last two hundred years.'

However, Burr (2003) and Wellard (2010) acknowledged that the identification of pathology does not sufficiently define disease and illness because the personal experience of disease and illness is influenced by cultural assumptions, norms and values, society's economics and power relations. Therefore, as the aim of this study was to explore the experience of T1D self-management in hospital, the social construction of health and illness within the hospital may influence the individual's experience.

3.3 Theoretical underpinning

3.3.1 Symbolic Interactionism

Symbolic interactionism is the theoretical underpinning of the study and like constructionism is embedded in the interpretive paradigm (Crotty 1998). George Herbert Mead (1934) introduced the idea of symbolic interactionism when he identified that people develop their sense of self through their interactions with others and then by associating meanings to objects and actions. Herbert Blumer (1969), who was a sociologist and a supporter of Mead, further explained symbolic interactionism as a way of viewing the social world, which, he believed individuals create through both individual and collective actions.

Blumer (1969, p.3) offered three basic premises of symbolic interactionism.

1. 'Human beings act towards things on the basis of meaning that they have for them
2. The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows [sic][4]
3. These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he [sic] encounters'.

Charmaz (2014, pp. 270 - 271) extended and clarified Blumer's three premises of symbolic interactionismby stating:

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[4] [sic] inserted here as focus of Blumer's (1969) definition is on male gender rather than all human beings. As the information is a direct quote it was not altered.

1. ‘Meanings are interpreted through shared language and communication’ (Charmaz 1980, p. 25)
2. ‘The mediation of meaning in social interaction is distinguished by a continually emerging processual nature’ (Charmaz 1980, p. 25)
3. ‘The interpretive process becomes explicit when people’s meanings and/or actions become problematic or their situations change’ (Charmaz 1980; Snow 2002).

An important principle of symbolic interactionism is the inseparability of the individual and the context in which that individual exists (Blumer 1969; Crooks 2001), consequently truth is seen as provisional. Meaning depends on the individual and the context which changes for the individual, as the context changes (Blumer 1969; Crooks 2001). Symbolic interactionism is therefore a study of the intersection of interaction, personal experience and social structure in a particular moment in time (Denzin 1992).

Within symbolic interactionism, self is defined by the social roles an individual inhabits (Blumer 1969) and it is these social roles that enable individuals to experience and understand their world (Chenitz & Swanson 1986). Social interaction and life are experienced by the symbols and meanings attached to these interactions (Blumer 1969), including verbal and nonverbal gestures, clothing and artefacts (Cutcliffe 2000). Symbolic interactionism therefore attempts to understand the symbolic meanings of things by recognising that language and symbols shape meanings and actions (Charmaz, 2014). Overall, symbolic interactionism emphasises that individuals and groups are active participants in creating meaning within situations (Patton 2002), as people, individually and within groups, construct their realities from the symbols around them through interaction (Cutcliffe 2000).

Charmaz (2014) indicated that symbolic interactionism is a dynamic theoretical perspective which views human actions as constructing the self, situation and society. Charmaz (2014) described symbolic interactionism as consisting of an abstract theoretical framework of premises and concepts for viewing social realities. Within social realities, interaction is seen as an ingrained dynamic and interpretive process which ‘addresses how people create, enact and change meanings and action' (Charmaz 2006, p. 7). Therefore, according to Charmaz (2014) symbolic interactionism:

1. Sees human beings as active agents engaged in practical activities
2. Emphasises how people accomplish these activities
3. Produces a dynamic understanding of actions and events.

In this way, symbolic interactionism provides a perspective to study people with T1DM and their experience of self-management in hospital, because it allows for an exploration of the complex processes through which the participants understand, interpret and create their world (Byrne & Heyman 1997).

3.3.2 Symbolic Interactionism and constructivist grounded theory

Symbolic interactionism therefore aligns with CGT method as the *constructivist* grounded theorist has a desire to 'gain a thorough understanding of particular phenomena within certain contexts' (Grbich 1998, p.28). Symbolic interactionism impels us to study language, including our own, and to question how language shapes what we ask, see, and tell in order to achieve understanding. According to Charmaz (2014, p. 278) grounded theory 'provides the methodological momentum for realizing the potential of symbolic interactionism for empirical research'. Charmaz (2014) believes that symbolic interactionism combines both theory and method into a coherent unified whole and as a result, grounded theory method and symbolic interactionism fit together and complement each other along with having the ability to advance each other. Furthermore, the symbolic interactionist perspective supports the kind of reflexivity required by the CGT researcher (Charmaz 2014).

As the concept of self is significant to symbolic interactionism it seems reasonable to adopt this theoretical underpinning when the aim of the research is to explore individuals' experiences of TID self-management and how they construct self-management. As the study aimed to explore people with T1Ds'experiences in hospital, it was foreseeable that these interactions with others within the hospital environment would form meanings for the participants' experience within the context of being a patient.

Aspects of symbolic interactionism explored in the study include the notion that 'meanings stem from interactions with others' and 'people's meanings are modified through the interpretive process' that assist people to 'make sense of and manage their social worlds' (Blumer 1969: Munhall 2007, p. 242). Symbolic interactionism enables an understanding of how meanings are constructed for the participants with T1D through their interactions with health professionals in hospital, mostly from gestures and language, and the perspectives behind these interactions (Cutcliffe 2000). A symbolic interactionist approach helps reveal what influences participants' interpretations of their interactions in hospital, particularly when they view themselves as the expert on their usual T1D self-management routine.

3.4 Research Methodology

3.4.1 Background of grounded theory method

Grounded theory is predominantly a qualitative research inquiry method which constructs a theory from the generated data, which provides an understanding of a particular phenomenon (Glaser & Strauss 1967; Strauss & Corbin 1998; Cutcliffe 2000; Heath & Cowley 2004; Polit & Beck 2004; Charmaz 2014). Grounded theory method was originally developed by Barney Glaser and Anselm Strauss following the death of one of their parents, which resulted in the study of death and dying in hospital and the subsequent publication *Awareness of Dying* (Glaser & Strauss 1965). Glaser and Strauss (1967) described grounded theory method in their seminal text, *The discovery of grounded theory: strategies for qualitative research*. The main focus of their grounded theory research was on the methods used to analyse data and from this focus 'they developed systematic methodological strategies' for other researchers to follow in the development of theories from qualitative data (Charmaz 2014, p. 5). Glaser and Strauss wanted to shift qualitative studies from being only descriptive to the development of theories that would provide conceptual understandings of the phenomenon being researched (Charmaz 2014).

Glaser and Strauss ended their union in the late 1980s (Charmaz 2014). Glaser continued to promote the classical grounded theory method. Strauss, who had an underlying sociological background, forged a less traditional grounded theory method with Juliet Corbin in the 1990s

(Strauss & Corbin 1998: Charmaz 2014). Strauss and Corbin described their interpretation of grounded theory method as evolved (Strauss & Corbin 1998). They argued that there are multiple perspectives and truths that are to be acknowledged as opposed to the classical grounded theory that suggests the discovery of truth emerges from data which represents truth (Strauss & Corbin 1998; Mills, Bonner & Francis 2006). Strauss was therefore responsible for the initial development of the *constructivist* thread in grounded theory method.

Kathy Charmaz, a student of Glaser and Strauss, continued to evolve the CGT method. Charmaz (2014, p. 12) acknowledged her CGT method ‘adopts the inductive, comparative, emergent and open-ended approach of Glaser and Strauss’s (1967) original statement’. Thus, while Charmaz adopted these methodological strategies from an earlier grounded theory version, a point of difference for her CGT was the integration of relativity and reflexivity while conducting the research (Charmaz 2011). Her method also includes the pragmatist tradition of there being an emphasis on action and meaning, which aligns with Strauss’s symbolic interactionism perspective (Charmaz 2014).

Charmaz (2006) defined grounded theory methodology as a ‘systematic, inductive and comparative approach for conducting inquiry’ with the purpose being to construct a theory from the collected data; the grounded theory. Charmaz (2000, p. 524) indicated data does not provide a window into reality but the ‘discovered reality arises from the interactive process and its temporal, cultural and structural contexts’. Charmaz is a known expert of CGT method due to her use of the method for conducting her own research since the 1990s along with her being a prolific publisher in the area (Charmaz 1990; 2006; Bryant & Charmaz 2007; Charmaz 2008; 2014).

3.4.2 Constructivist grounded theory

Charmaz (2014, p. 342) defined CGT as:

> ‘A contemporary version of grounded theory that adopts methodological strategies…of the original statement of the method but shifts its epistemological foundations and takes into account qualitative inquiry occurring of the past 50 years’.

CGT method uses an abductive process in order to construct the grounded theory rather than a deduction of hypothesis from an existing theory (Charmaz 2014).

Previous iterations of grounded theory method indicated a literature review (see 2.2 on page 14) should not be undertaken until all the data has been collected and analysis commenced as to not jeopardize the researcher's ability to analyse the data in a non-biased manner for the generation of theory (Glaser & Strauss 1967). However, Charmaz's CGT method recognises the existence of the researcher's prior knowledge and views the researcher as a co-constructor of the theory rather than the theory being generated solely from the data (Charmaz 2014). CGT therefore focuses on both the researcher's and research participants' language, meanings and actions.

The CGT method therefore:

1. assumes a relativist approach
2. acknowledges multiple standpoints and realities of both the grounded theorist and the research participants
3. takes a reflexive stance toward our actions, situations, and participants in the field setting, and constructions of them in our analyses
4. situates research within historical, social, and situational conditions of its production (Charmaz 2014).

3.4.3 Use of constructivist grounded theory

Charmaz (1990) specifically supported using grounded theory method for 'studying the experience of chronic illness' (p. 1161)[5]. In particular this method fits the purpose of this study, to construct a substantive theory which explores and explains the experiences of self-management for patients with T1D in hospital. People living with a chronic condition such as T1D construct their understanding of their condition through their lived experiences, including where they have those experiences. For example, the person with T1D experiences their chronic condition at home, at work and during interactions with health professionals. Therefore, people with T1D experience the

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[5] While this quote uses the terminology of chronic illness I recognise the current accepted terminology in an Australian context is chronic condition (Wellard 2010; Department of Health 2017).

construction of their illness as their reality (Charmaz 1990). On some occasions, how individuals construct their chronic condition can be challenging or contradictory to how the health professionals construct the same chronic condition (Charmaz 1990; Martin & Peterson 2009).

As the aim of the study was to explore the self-management experiences of people with T1D in hospital, Charmaz's (2006; 2014) CGT method was selected as the most appropriate methodology. Charmaz (2006) uses a social constructionist and symbolic interactionist approach within the grounded theory method, which enables an interpretation of people's experiences, such as self-management of T1D in hospital. Charmaz advocated for a social constructionist approach to grounded theory method within the interpretive paradigm (Charmaz 2006; Carroll 2008; Charmaz 2014). Charmaz's (2006; 2014) interpretive approach to theorising allows for indeterminacy, which is a feature of human interaction, rather than a sign of confusion. The CGT method is, therefore, compatible with both social constructionism and symbolic interactionism (Charmaz 2006; 2014).

Charmaz (2006) also supports the use of grounded theory method when little is known about a phenomenon, such as the current study, as the methodology encompasses a context-bound approach and seeks to understand social processes linked to a given phenomenon. Therefore, grounded theory addresses knowledge gaps by constructing a theory that interprets and explains the study participants' accounts of their actions (Birk & Mills 2011; Charmaz 2014).

3.4.4 Weakness/Common problems of the method

As with all methodologies, there are some recognised weaknesses using the grounded theory method (Charmaz 1990). Charmaz (1990, p. 1164) provided the following examples:

- 'Premature commitment to analytic categories; issues, events and meaning are not fully explored
- The use of unnecessary jargon when labeling categories
- Lack of clarity about key terms such as theory, category and saturation'.

The majority of criticisms surrounding the method are related to misunderstanding or misuse of the method and researchers glossing over epistemological assumptions and minimising its relationship to sociological theory (Charmaz 1990). The glossing over, leads to a weak theory being constructed by not following through with conceptual analysis. As a result, researchers using the grounded theory methods fail to generate a theory that is grounded in the data. Chapter four demonstrates how the core tenets of grounded theory were used to construct a substantive grounded theory in the current study.

3.5 Chapter summary

Chapter three provided an overview of the epistemology, theoretical underpinnings and method used to conduct the study. Social constructionism and symbolic interactionism were discussed along with how they underpin and inform the chosen CGT method. Chapter four provides details of the specific methods used to conduct the CGT study. Areas addressed in the following chapter include ethical considerations, sampling and recruitment of participants, data generation and the use of constant comparative data analysis. Additional core tenets used in the constructing of the substantive grounded theory are also outlined. Chapter four also addresses the criteria used to evaluate the rigour of the CGT study.

Chapter Four: Methods

4.1 Chapter overview

Chapter three discussed the methodology chosen for the study, constructivist grounded theory (CGT), along with the underlying epistemology of social constructionism and theoretical underpinning of symbolic interactionism. Chapter four provides details of the methods used to generate and analyse the data in order to construct a substantive grounded theory. Charmaz (2006, p. 2) suggested 'grounded theory methods consist of systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories 'grounded' in the data themselves'. While these guidelines exist, they offer general principles and heuristic devices to guide researchers and are not a formula for grounded theory (Charmaz 2006). The process of data generation, data analysis and theory development explained in chapter four occurred in a continuous and circular manner in order to ensure the core processes of CGT were followed. The following discussion will include my position as the researcher, ethical considerations for the study, sampling methods, participant recruitment, data generation, data analysis and theory construction along with the ways rigour was established in the study.

4.2 Positioning of myself as the researcher

As previously discussed in the Thesis synopsis (see 1.6 on page 11) I chose to write in the first person in order to acknowledge myself as a co-constructor of the study (Charmaz 2014). CGT research recognises the researcher influences and shapes the data rather than the data being separate from the researcher and waiting to be discovered. Therefore, I needed to acknowledge my contribution through my interpretation of the data in the generation of the substantive grounded theory (Charmaz 2014).

In addition to acknowledging myself as a co-constructor of the research, I also needed to acknowledge the influence of my professional, academic and research background (Hoare, Mills & Francis 2012). Charmaz (2006; 2014) suggested the researcher's background has the potential to impede or encourage the emergence of codes and categories from data, which can lead to the researcher's bias influencing the development of the theory. During the construction of the thesis, I was a Lecturer in Nursing, with a diabetes focus, and my main area of teaching and research was in diabetes management and education. Previously I was employed as a Registered Nurse in an acute care setting and viewed first hand a number of constraints being enforced by health professionals on a person being able to self-manage in hospital. In addition, my previous experience of living with a person with T1D influenced my decision to choose to study an issue related to T1D.

In order to manage both my professional and personal interest bias on the study it was imperative that I adopted reflexivity in my research (Birks & Mills 2011; Charmaz 2014). Charmaz (2006) indicated constructivist grounded theorists are obliged to include reflexivity in their research design. Reflexivity will be discussed in further detail within this chapter (see 4.9 on page 69).

Another aspect of my position as the researcher was to consider the sensitising concepts that influenced the research. Charmaz (2014) described sensitising concepts as the initial, yet tentative, ideas a researcher has and these enable the development of the questions needed to explore their chosen topic. These sensitising concepts provide a starting point for inquiry and a loose frame for exploring such interests (Blumer 1954; Charmaz 2014). For me these sensitising concepts developed from both my professional and personal interest in self-management of T1D in hospital and my previous Honours research on the phenomenon (Munt 2009). However, I was careful to build on my previous knowledge and Honours research by undertaking a broad preliminary literature review in order to develop the aim of the proposed research. These sensitising concepts, such as the expert patient, were also used as ‘points of departure’ to develop interview questions, to listen to the person being interviewed and to look closely and think analytically about the data (Charmaz 2014, p. 31). Using my personal interests, sensitising concepts and both my clinical and academic perspective enabled me to develop my ideas while conducting the study.

Below is a figure (Figure 1), which visually represents the methods used to construct the substantive grounded theory of the study. The components of the figure are explained in more detail throughout the chapter.

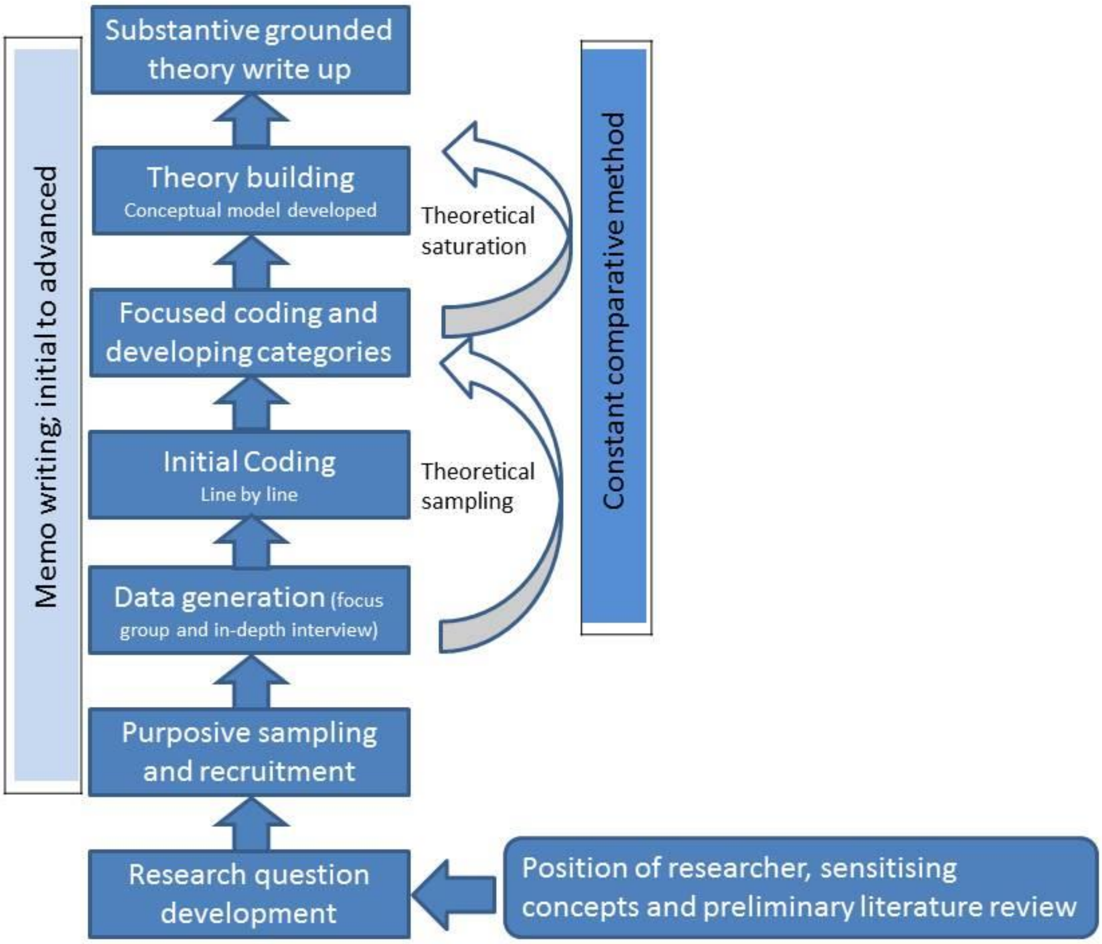

Figure 1: Constructivist grounded theory diagram used for the study

[6]

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[6] I developed the figure (Figure 1) based on a figure that appears in Charmaz's *Constructing Grounded Theory* textbook (2014, p. 18).

4.3 Ethical considerations

Due to the evolving nature of grounded theory studies, identifying possible ethical issues prior to generating data can be problematic because the data may lead to the researcher exploring areas with differing ethical requirements (Birks & Mills 2011). However, as qualitative research involves delving into a person's life there are a number of considerations required to ensure the rights of the participant are respected (Schneider, Whitehead & Elliot 2007). Therefore, following the principles of beneficence, non-maleficence, respect for human dignity and justice were important in the study (Taylor, Kermode & Roberts 2006). How these principles were addressed in the study will be explored in more detail below. By following these principles, along with being willing to accept the participant's potential decision to withdraw from the research prior to analysis beginning, ensures the dignity and well-being of the participant takes precedence over the expected knowledge gain. All National Health and Medical Research Council (NHMRC) guidelines for conducting ethical research with humans were followed in the study (NHMRC 2007).

Ethics approval for the study was granted by the Flinders University Social and Behavioural Research Ethics Committee (SBREC) Project Number 5066 (see Appendix 4 on page 248). Ethics approval was sought in two different stages. Initially, ethics approval was granted for the Focus group component of the study and then a modification was submitted to the Ethics committee prior to the commencement of the in-depth interview component of data generation. The ethics modification included an interview schedule and the initial interview questions, which were also approved by the SBREC.

4.3.1. Beneficence and non-maleficence

In ethically sound research the aim of the study is to achieve beneficial outcomes for individuals and/or the community (Schneider, Whitehead & Elliot 2007). The study aimed to provide new knowledge and understanding about how people living with T1D experience their diabetes self-management in hospital. Hence, the generation of new knowledge from the study could potentially benefit people living with T1D during hospitalisation in the future as well as the health professionals in the provision of appropriate clinical care.

In order to ensure no harm was caused to participants during the generation of data, potential risks to participants were monitored by interpreting both verbal and non-verbal cues (Focus group only). While qualitative research is considered non-invasive because there is no intervention conducted to potentially cause harm, the invasion of the psyche can pose risk to the participant (Munhall 2007). Therefore, I planned to reduce potential harm by ensuring all participants were informed that they had the right to refuse to answer any particular question or withdraw from the research prior to data generation commencing. If any participants showed signs of distress during the data generation, the focus group or interview would cease and only resume once the participant verbally agreed they were able to comfortably continue to participate. In case a participant did became distressed there was a strategy in place to refer the participant to a free online Diabetes Counselling service.

The accurate portrayal of participant's points of view is important in ensuring no harm was caused to any of the participants. The accurate portrayal of the participant's views was addressed, for example, by seeking clarification of their responses from the participants to ensure that what they were saying was being accurately recorded and represented. This is discussed further in In-depth interviews (see 4.5.2 on page 63).

4.3.2 Informed Consent (Respect for human dignity)

Informed consent was a requirement of all participants in the study (Taylor, Kermode & Roberts 2006; Richardson-Tench 2014). Obtaining informed consent ensures that the participant's human dignity is respected by the researcher. As the participants were over 18 years of age, they were legally capable of providing their own consent (Schneider, Whitehead & Elliot 2007). Prior to being involved in the study, all participants were provided with a Letter of Introduction (see Appendix 5 on page 250) and a detailed Information Sheet about the study (see Appendix 6a & b on pages 252 & 254). As part of the consent process I determined each participant's level of comprehension of the study and their understanding of their rights as a participant. This process occurred prior to participants being involved in data generation either in person, for those participants taking part in the focus group, or via telephone for those participants taking part in the in-depth interviews. I answered all participants' questions prior to the participants signing their informed consent form (see Appendix 7a & b on page 257 & 259). In this way, I ensured that the participants were giving informed consent to participate thereby reducing the risk of harm to participants.

4.3.3 Confidentiality (Justice)

Confidentiality, as a principle of justice, was a major consideration for the research. Maintaining confidentiality of the research participant is an important aspect of conducting ethical research (Taylor, Kermode & Roberts 2006; Schneider, Whitehead & Elliot 2007). In reporting the research, all participants were allocated a pseudonym to ensure their confidentiality was maintained. On some occasions, participants mentioned the name of the hospital they were admitted to and these references were de-identified in order to protect the hospitals from being identified and the participants from potentially being identified. De-identification was particularly important in protecting the confidentiality and anonymity of participants who had lodged letters of complaint following their discharge. Furthermore, the hospitals and the health professionals were protected from being identified as they were not given an opportunity for a right of reply within this study.

All participant data were stored as per the Flinders University SBREC requirements and only I had access to the data as the Principal researcher. The demographic data, audio recordings and transcripts were stored in a de-identified format on a password protected computer in my locked office at Flinders University. Hard copies of any participant information or collected data were stored in a locked filing cabinet in my office to which only I had access. The data from the study will be confidentially destroyed following the five year storage period required by the SBREC.

While I transcribed the audio-recording of the focus group verbatim, an external transcription service transcribed the audio-recorded interview data verbatim. The transcription service used for the study was bound by a confidentiality clause ensuring the participant data were not at risk.

4.4 Sampling and Recruitment

Purposive sampling was initially used to ensure participants were able to provide insight into the phenomenon being explored (Charmaz 2006, Birks & Mills 2011; Charmaz 2014). Qualitative researchers are known to use purposive sampling to ensure their study contains suitable participants, such as people with T1D experiencing a recent admission to hospital, to meet the aims of the research (Polit & Beck 2004; Charmaz 2006). I wanted to undertake the study to understand how people with T1D assigned meanings, explanations and interpretations to their experience of self-management in hospital.

Theoretical sampling was later utilised in the study when re-interviewing participants in order to saturate category properties. Theoretical sampling is discussed later in the chapter (see 4.8 on page 69).

4.4.1 Recruitment for focus group

Recruiting participants for the focus group was undertaken by advertising to Diabetes SA (South Australia) members (see Appendix 8a on page 261). The screening criteria for participation in the study included the following questions:

- Do you have Type 1 Diabetes?
- Are you over 18 years of age?
- Have you been admitted to hospital in the last 2 years for a condition other than your diabetes? For example, have you had elective or emergency surgery that required you to be in hospital?

In addition, I presented general information about the study to people with T1D at a Diabetes SA refresher day and provided more specific information to those who expressed an interest in being involved. People who expressed interest in participating in the study were emailed a Letter of Introduction (see Appendix 5 on page 250), an Information Sheet (see Appendix 6a on page 252) and a Consent form (see Appendix 7a on page 257) to participate in the focus group.

4.4.2 Recruitment for in-depth interview

Recruitment for in-depth interview participants was initially undertaken following approval by the Australian Diabetes Educators Association (ADEA) to access their members (see Appendix 8b on page 263). This approval allowed me to invite ADEA members to forward recruitment information to people they knew living with T1D. The study was also approved to be advertised on a website named *Reality Check*, specifically for people with T1D. Employees of Diabetes Victoria and Type 1 Network contacted me after seeing the original advertisement for the study and requested to share the information on their websites and social media sites. Some blog sites specifically for people with T1D also requested permission to advertise my study on their blogs. Some of the interview participants indicated they forwarded my contact details to people they knew with T1D because they had a recent experience of self-managing their diabetes in hospital. People who expressed interest in participating in the in-depth interviews for the study were emailed a Letter of Introduction (see Appendix 5 on page 250), an Information Sheet (see Appendix 6b on page 254) and a Consent form (see Appendix 7b on page 259).

4.4.3 Selection Criteria

There were specific inclusion and exclusion criteria for the participants in both the focus group and in-depth interview components of the study, which are tabled on page 60 (Table 1).

Table 1: Participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• a diagnosis of T1D • be 18 years or older • be able to communicate in English in both verbal and written forms • a non diabetes related hospital admission within the previous two years • be cognitively able to understand the study in order to provide informed consent • living with T1D for > 5 years	• younger than 18 years of age • unable to speak or comprehend English • being acutely unwell in hospital • having an intellectual or mental impairment • being admitted to hospital for their T1D • be cognitively unable to understand the study • individuals in a dependent or unequal relationship with the researcher

There was a specific rationale for only including people 18 years and older. People over the age of 18 are thought to be better able to self-manage than a child or adolescent (Song 2010). In addition, the requirement of parental consent for people younger than age 16 could bias the study because the child may not be recognised as an independent self-manager. Furthermore, researchers suggest that adolescents tend to be a high risk cohort with regard to neglecting their T1D self-management (Paterson & Thorne 2000a), thus they were excluded from this study. Participants were required to have been living with a T1D diagnosis for more than five years and have an established self-management routine.

People who were acutely unwell in hospital were excluded from the study because they may not be physically or mentally able to care for their own diabetes while in hospital and would likely be required to relinquish their overall care to health professionals (Noschese et al 2009). Additionally, a patient admitted for a condition specifically related to their T1D, such as an episode of diabetic ketoacidosis, may require health professionals' support to manage their condition until stabilisation occurs, consequently they may not be able to self-manage in this context (Flanagan & Watkinson

2012). Therefore, to meet the inclusion criteria, participants were required to have been admitted to a general medical or surgical ward with a primary admission diagnosis other than T1D.

People with an intellectual or mental impairment were also excluded from the study because they may not have full self-management responsibility of their T1D and/or may not be able to articulate their experiences of T1D self-management in hospital (Flanagan & Watkinson 2012; Flanagan et al 2018). Qualitative research revolves around the person's ability to convey their experience so if the participant is unable to articulate their experiences due to communication difficulties, including severe listening or sight issues, they would not be able to contribute to meeting the aims of the study. Finally, individuals in a dependent or unequal relationship with the researcher were eligible to participate in the study in order to avoid the potential coercion of participants as well as to circumvent influencing or biasing the research findings.

4.5 Data generation

The aim of the study was to explore the experience of self-management of people with T1D while in hospital. In order to achieve this aim the data needed to be richly detailed to enable the occurrence of in-depth analysis, which is essential for the constant comparative analysis process in grounded theory (Birk & Mills, 2011). Charmaz (2014) suggested grounded theory method can utilise a number of methods to generate data due to its flexible nature. The methods used to generate rich data for this study were one focus group and fifteen in-depth interviews.

4.5.1 Focus group

The initial data generation method, a focus group with five participants, was conducted in order to generate, shape and validate the semi structured questions for the in-depth interview. The rationale for using a focus group was to ask broad questions and seek feedback from the participants about whether the questions, based on sensitising concepts, were relevant to their self-management experience. The decision to use the focus group to generate interview questions is an example of my reflexivity in action within the research process as it moved me away from relying on my assumptions and pre conceived ideas developed from my previous research on T1D self-management in hospital.

Birks and Mills (2011) support the use of focus groups in grounded theory to generate concepts that will be followed up during in-depth interviews, as was the case in the study. Furthermore, Charmaz and Liska Belgrave (2012) asserted that combining focus group and interview data has been effective in generating grounded theories, which further supports my decision to use both data generation methods.

A known disadvantage of using focus groups is that some participants may feel less comfortable than others to share their personal experiences within a group, thus affecting their capacity to contribute (Birks & Mills 2011). Therefore, it was important, as the facilitator of the group, that I monitored the contributions individuals made and their interactions with others in the group. On those occasions when a participant did not seem to be contributing as freely as others, I would gently ask the person what they thought about a point of discussion or whether they had a similar or different experience to draw them into the conversation. Establishing rapport and developing group norms prior to the focus group commencing also helped increase the comfort levels of the participants, thus encouraging them to actively contribute (Birks & Mills 2011).

The focus group was audio recorded and focused on self-management experiences in hospital using a draft set of questions developed from the preliminary literature review and from my Honours study (Munt 2009) (see Appendix 9 on page 264). The focus group ran for approximately 90 minutes. I transcribed the focus group audio-recording verbatim enabling me to familiarise myself with the data from each participant. Throughout the focus group I took additional notes, which enabled me to ask specific follow-up questions relevant to the discussion in the group or to seek clarification from participants (Charmaz 2006).

The focus group participants were asked to answer the draft in-depth interview questions to shape and refine the questions for the in-depth interviews. What became apparent from the focus group participants was that I had initially included too many specific questions and some leading questions. As a result I focused on a few broad questions in my initial interviews in order to reduce my bias from specific and leading questions (see Appendix 10 on page 266). I then integrated some of the more specific draft questions as part of the interviews as an aspect of theoretical sampling.

4.5.2 In-depth interviews

Following the focus group, the initial broad interview questions were developed for the second component of data generation (see Appendix 10 on page 266). According to Birks and Mills (2011) an extensive number of grounded theory studies rely on interviews to generate data, which demonstrates the value of using interviewing to construct a theory. In-depth interviewing fits with the underlying epistemology of CGT because the interview is a mutual interaction that leads to the co-construction of meaning (Minichiello, Aroni & Hays 2008; Charmaz 2014). In her textbook *Constructing Grounded Theory*, Charmaz (2014) described in detail the use of in-depth interviews and I consistently referred to this text while interviewing in order to guide the process.

The study used in-depth interviews with 10 people living with T1D who had experience self-managing their T1D in hospital within the last two years. All participants were asked to complete a demographic questionnaire prior to the interview (see Appendix 11 on page 267). The questions enabled me to gain an understanding of their diabetes background and to work on developing rapport with the participants through discussing their demographics. The audio recording of each in-depth interview varied with the shortest being 37 minutes and the longest being 63 minutes.

In-depth interviews enable participants to have a relatively free discussion about their attitudes, beliefs, experiences and actions around T1D self-management in hospital (Strauss & Corbin 1998; Polit & Beck 2004; Taylor, Kermode & Roberts 2006; Charmaz 2014) .In order to encourage free discussion broad open-ended interview questions were used at the beginning of each interview (Charmaz 2014) (see Appendix 10 on page 266). An initial open-ended question: ‘Can you please tell me what self-management means to you?’ was used in the study. Using these types of broad questions encourages participants to express their views, experiences and actions, which is an important element in CGT (Charmaz 2014). Following the first three interviews, I added several more specific questions to the broad interview questions to explore the codes that were emerging from the data (see Appendix 12 on page 269). This is an example of theoretical sampling (see 4.8 on page 69) (Chiovitti & Piran 2003; Charmaz 2014).

I conducted telephone interviews for all of the in-depth interviews because the majority of participants were located outside the metropolitan area of Adelaide, or interstate. Birks and Mills (2011) stated logistical issues lead to the requirement for telephone interviews and the potential for missing non-verbal cues needs to be acknowledged. As a result, the reliance of interpreting verbal cues in telephone interviews was significant for the current grounded theory research. I ensured I listened carefully to the participants and tried to pick up on any changes in their verbal communication style. An example of changes in communication was when participants altered their tone of voice to indicate they were using some sarcasm in their response. The example below is from one participant who was explaining how people thought she had unstable diabetes and that is why she 'qualified' for a pump.

> *….Or you have to have really unstable diabetes. They're the only people that qualify for pump therapy, and I'm using those terms, obviously, in inverted commas (Trish Int. 5)*
>
> *Oh yes, yes, I totally understand that over phone that that is exactly what you were meaning (Me).*

Recording the telephone interviews assisted me to interpret missing non-verbal cues because the recording can be listened to multiple times and sighs, hesitations 'and intonation or emotion' can be easily heard (Ward, Gott & Hoare 2015, p. 2780).

Prior to the interviews commencing I informed participants that I would be listening intently to their responses and in order to not interrupt them I would take notes in case I needed to follow up or clarify their responses (Charmaz 2006). To ensure I correctly interpreted their definitions and meanings, I asked probing questions such as 'Can you tell me more about that?', or clarifying questions such as 'Do you mean …?' (Charmaz 2014). This strategy helped me ensure the participant and I had the same understanding of what they were saying and that I was not forcing my interpretation onto the data (Charmaz 2006).

4.6 Data analysis

I used constant comparative data analysis to analyse the focus group and in-depth interview data (Charmaz 2006; 2014). Constant comparative data analysis occurs concurrently with the generation of data and is a core tenet of CGT (Cutcliffe 2000; Heath & Cowley 2004; Charmaz 2006; Weust 2007).Charmaz (2014, p. 342) defined constant comparative analysis as a method that:

> 'generates successively more abstract concepts and theories through the inductive process of comparing data with data, data with code, code with code, code with category, category with category, and category with concept'.

Following this process, I compared major categories with the literature in the final stages of constant comparative method (Charmaz 2014). Therefore, constant comparative data analysis enabled me to construct a theory grounded in the data (Botsford, Clarke & Gibb 2012). Overall the data generated from the participants, along with my active participation in the CGT study, led to the co-construction of the data and the consequent construction of the substantive grounded theory (Charmaz 2006).

4.6.1 Coding the data

Coding data is a core tenet of grounded theory and enables the researcher to interpret meaning and action from the data (Charmaz 2014; 2015). Variations of coding methods exist among the different grounded theory methods. However, I was following Charmaz's CGT, therefore, I used her coding methods. Charmaz (2006) explained coding in a less prescriptive and more flexible manner, compared to the prescriptive methods of Glaser and Strass (1967), while specifying the core tenets of grounded theory analysis still need to be followed.

Charmaz (2014) acknowledged the researcher constructs the codes from their interpretation of their participants' data in a CGT approach. Codes are names allocated to the data and are derived from the researcher's previous knowledge and experience; preconceived codes (Charmaz 2014; Giles, deLacey & Muir- Cochrane 2016, E32). The transcribed data in the study was coded line by line, focused codes were identified and categories were constructed (Charmaz 2006; 2014).

4.6.2 Initial coding, focused coding and categorisation of data

Charmaz (2006; 2014) described two main types of coding in CGT with the first being initial, or line-by-line, coding. The focus group and in-depth interview data for the study were coded line by line, using gerunds, in order to begin the analysis of what was happening in the data and allocate some analytical meaning to the data (see Figure 2 on page 66) (Charmaz 2006; Charmaz & Liska Belgrave 2012; Charmaz 2014). Gerunds are the verb form of nouns, which are used in coding to actively name the data; they denote action (Hoare, Mills & Francis 2012; Charmaz 2014).

Transcribed data	Initial codes
Facilitator: How do you know that they don't feel that you're capable? What sort of indication do they give you that they don't think you're capable of managing yourself?	
Alison: In this specific instance I had already arranged with the anaesthetist that when I was *compos mentis,* I could go back on the pump and I could manage things myself. I had to fight the staff to let me do it.	Making arrangement with anaesthetist for management when awake Going back on the pump post op Being able to manage pump myself Fighting the staff to SM

Figure 2: Initial coding example

This coding method was carried out in a quick spontaneous manner, as recommended by Charmaz (2014), to ensure the coding stuck closely to the data. In other words, the coding was grounded in the data. As suggested by Hoare, Mills & Francis (2012) the initial coding method is significant in preserving the experience of the participants. Therefore, initial coding allowed me to undertake a close analysis of the data and conceptualise ideas at a beginning level, which enabled me to shift the data from being simply descriptive to being more abstract.

The second type of coding was more focused to enable me to sift, sort, synthesise and analyse large amounts of data (Charmaz 2014). Within focused coding I identified the initial codes, which appeared to capture much of the initial data and seemed to have considered importance to the study aim (see Figure 3 on page 67) (Charmaz 2014).

Transcribed data	Initial code	Focused code
Facilitator: How do you know that they don't feel that you're capable? What sort of indication do they give you that they don't think you're capable of managing yourself?		
Alison: In this specific instance I had already arranged with the anaesthetist that when I was *compos mentis,* I could go back on the pump and I could manage things myself. I had to fight the staff to let me do it.	Making arrangement with anaesthetist for management when awake Going back on the pump post op Being able to manage pump myself Fighting the staff to SM	Negotiating care Contesting care Encountering resistance

Figure 3: Focused coding example

Giles, de Lacey and Muir-Cochrane (2016) indicated the focused codes are more selective and conceptual and are developed through an increased level of data analysis. However, the process of initial and focused coding was essentially a cyclical process with continual interactions between the initial and focused codes, which is constant comparison.

These focused codes were then compared to larger portions of data in order to generate tentative categories (Charmaz 2014). As I coded the data, I collapsed some codes into higher levels of abstraction and developed tentative categories that encapsulated and accounted for large amounts of data, which explained the thoughts and behaviours of the participants when undertaking T1D self-management in hospital.

4.7 Memo writing

Another core tenet of grounded theory is memo writing, which is essential to developing ideas that emerge from the codes grounded in the data (Charmaz 2006; Thornberg 2012; Charmaz 2014). Memo writing is an ongoing activity in grounded theory and over time the memos help researchers reach a higher level of abstraction, which assists with constant comparison and enables theory construction (Charmaz 2014). As a result, memo writing has been described as intellectual capital in the bank. It also contributes to the audit trail of decision-making of the researcher as well as being a ‘record of the researcher’s developing theoretical sensitivity’ (Hoare, Mills & Francis 2012, p. 243).

According to Charmaz (2006) memo writing is a way to compare data, explore ideas about the codes, and assists in directing further data generation. In the study, I used memo writing concurrently with data generation and constant comparative analysis to verify my thoughts of what was being said in the data and to assist me to theorise about what was happening in the data (Charmaz 2006; Birks and Mills 2011; Thornberg 2012). I wrote memos in multiple formats, handwritten, word processed and voicemails to myself, and they were recorded at all differing times of the day, even during the middle of the night. Initial memos were written to record my thoughts about the data, the codes I had allocated and any thoughts I had on areas to explore in subsequent interviews. The initial memos were descriptive in nature so were only at a beginning level of analysis (see Appendix 13 on page 270). As the data generation progressed so did the level of analysis in the memos, which shifted from a basic descriptive level to a higher level of analysis (see Appendix 14 on page 275). These memos were used to help me raise the focused codes to the conceptual categories (Charmaz 2014).

4.8 Theoretical sampling

Through memo writing, incomplete categories and gaps can be identified, which then spurs theoretical sampling. As defined by Birks and Mills (2011, p. 70):

> ‘Theoretical sampling provides direction for your next stage of data collection in a process of concurrent analysis that continues cyclically until categories are fully developed or saturated’.

In line with recommendations from Charmaz (2006), I used theoretical sampling to help refine and fill out the categories with selective data once the tentative categories were developed. An example of theoretical sampling in the current study was the alteration of the interview questions to narrow the focus of the questions to refine and fill categories. One tentative category was *limited interactions*. By asking focused questions in subsequent interviews about the types of interactions participants had with health professionals in relation to their T1D, I found participants had experienced limited discussions about their diabetes throughout their entire episode of care. This example of theoretical sampling led to development of the category of *experiencing limited diabetes discussions*, which captured the experience of the participants.

Another example of theoretical sampling was re-interviewing three participants who had initially been interviewed first, fourth and eleventh. The reason for selecting these specific participants was to ensure the categories were reflective of their experiences despite the initial order of their first interview. Re-interviewing these participants, once I had established the categories, enabled me to fill any final gaps in the categories I had identified by asking these participants specific questions about their self-management experiences in hospital.

4.9 Theoretical sensitivity and reflexivity

Theoretical sensitivity is seen as the ability to ‘define phenomena in abstract terms and to demonstrate abstract relationships between studied phenomena’ (Charmaz 2014, p. 161). A researcher’s theoretical sensitivity is personal in that it reflects their level of insight into both themselves and the area they are researching, and reflects their intellectual history, the type of theory they have read, absorbed and now use in their daily thought (Wong, Liamputtong & Rawson 2017).

Charmaz (2014) suggested sensitivity is gained through considering multiple vantage points, through making comparisons, following leads and building on ideas. In CGT, theoretical sensitivity is influenced by coding with the use of gerunds fostering theoretical sensitivity by nudging us from ‘static topics and into enacted processes’ (Charmaz 2014, p. 245). I gained my theoretical sensitivity by reading the related literature, through the coding process and category building, by reflecting on memos and through theoretical sampling. Furthermore, my theoretical sensitivity was also developed through my experience as a nurse and my previous research in the area of T1D self-management in hospital that I have acknowledged by being reflexive during the study.

Traditional grounded theory requires researchers to have a limit of pre-determined thoughts and knowledge in the area they are studying in order to not bias their analysis and to develop theoretical sensitivity directly from their emerging data (Mills, Bonner & Francis 2006). However, CGT recognises that researchers have professional knowledge and experiences, which requires them to be reflexive in order to minimise bias and to avoid imposing their thoughts onto the data (Charmaz 2014). Furthermore, researchers also need to focus on the participants’ experiences, beliefs and actions and not their own preconceived ideas to recognise their influences on the research (Charmaz 2014).

The process of initial coding assisted me to focus on the participants’ experiences rather than on any of my preconceived ideas. As stated by Schreiber (2001, p. 60) ‘what is needed is for the researcher to recognize her or his own assumptions and beliefs, make them explicit, and use GT [7]techniques to work beyond them throughout the analysis’. Using a focus group to determine the interview questions, as previously discussed in 4.5.1, demonstrates being reflexive because I was aware that my previous experience could influence the development of the interview questions. The use of memo writing was another method I employed which, enabled me to remain reflexive and reflective, along with discussions about interpretation of data and memos with my research

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[7] GT is the acronym for grounded theory in this quote by Schreiber (2001).

supervisors (Thornberg 2012; Giles, de Lacey & Muir-Cochrane 2016). Overall, reflexivity enables the credibility of the research findings ‘by making explicit the researcher’s contribution to the interpretive process through self-critical appraisal and self-awareness’ (Giles, King & de Lacey 2013, p. E. 34).

4.10 Theoretical saturation

Theoretical saturation occurs in grounded theory studies once the theoretical category properties are saturated with data (Charmaz 2014; Giles, de Lacey & Muir-Cochrane 2016, E. 40). Literature suggests that interviews can cease once theoretical saturation of the data occurs (Cutcliffe 2000; Chiovitti & Piran 2003; Charmaz 2006). Charmaz (2006; 2014) indicated theoretical saturation is reached specifically when no new theoretical insights of the identified categories emerge while gathering new data. While Charmaz (2014) suggested there is debate about the concepts of category saturation and sample size, she suggested researchers need to consider how the credibility of the research is affected by the researcher’s claims of category saturation.

Charmaz (2014) suggested 25 interviews was sufficient for data saturation in certain small projects, as long as the researcher is not making claims specific to human nature or which contradict established research. This current study was not attempting to make claims specific to human nature or to contradict existing established research but it was aiming to understand and explain the experience of self-management in hospital for people with T1D.

Overall the study included data generated from one focus group and 15 interviews. Following constant comparative analysis of 12 interviews many consistent codes emerged from the data and these were placed into tentative categories and then into a preliminary conceptual model (see Appendix 15 on page 277). After subsequent reviewing previous interviews and using the constant comparative data analysis method, it became apparent that no new properties were emerging. I then re-interviewed three participants in order to explore the major categories and sub categories with them to determine whether saturation of the categories had been met. In addition, I emailed all participants in the study with a conceptual model and summary of the key findings to ask their perspective on whether the categories were complete (see Appendix 16 on page 278). The majority of participants (12 out of 14) responded to the email and indicated that the model and key findings were clear to them and it was an accurate representation of their experiences of T1D self-management in hospital. Therefore, I believe saturation was met as I could find no further theoretical insights following these steps (Charmaz 2006).

4.11 Theoretical sorting and diagramming

Charmaz (2014) indicated the process of sorting, diagramming and integrating is an intertwined process in grounded theory, which leads to the construction of the substantive grounded theory. In the current study I followed Charmaz's recommendation (2014, p. 218) to 'sort memos by the title of the category', a process which filled my office table and walls with memos. The process enabled the comparison of categories, additional refinement of the categories and the creation of a logical order of the categories (Charmaz 2014). It also enabled me to see the relationships between the categories more clearly.

Following on from theoretical sorting I used diagramming to create visual images of emerging theories (Charmaz 2014). In relation to diagramming, I initially used 'post it' notes to represent each core category and I moved these around physically until I settled on their order, which enabled me to develop the conceptual model, which represented the generated data (see 5.3 on page 78). My initial diagram of the categories was drawn on the computer using 'smart art graphics', but I felt it did not adequately explain the lineal direction of the categories to the core category (see Appendix 15 on page 277). There were no arrows in the initial diagram to represent the influence each category had on another category. Further diagramming using 'smart art graphics' enabled me to determine the specific direction of the categories from the external influences (*hospital*), which led to a reliance on internal influences (*everyday*), which led to the core category (see Figure 4 on page 79).

4.12 Construction of the substantive grounded theory

The final step of the research process was to write up the substantive grounded theory (see Figure 1 on page 54) (Charmaz 2014). Constructivist grounded theorists aim to understand a phenomenon by identifying potential data patterns, comparing the information in memos and exploring theoretical ideas with relevant existing literature (Charmaz 2014). Through the use of the constant comparison data analysis method and memo writing, I developed the tentative categories that were further developed until they became refined (Giles, deLacey & Muir-Cochrane 2016).

Charmaz (2014, p. 189) stated ‘categories explicate ideas, events or processes within the data’. The focused coding and category development increased the level of conceptual analysis required to select the core category. While I simultaneously collected and analysed data, theoretical concepts began to emerge. As suggested by Charmaz (2014), these concepts, or core processes, were constantly compared during data analysis and were eventually developed into the substantive grounded theory. The chosen core category therefore encapsulates and explains the grounded theory.

In addition, I undertook a secondary literature review and the content was woven into the findings chapters in order to situate the study into existing literature as well as provide support for the substantive grounded theory. Therefore, through following the systematic application of the core tenets of grounded theory methods and processes, as discussed in this chapter, several core concepts emerged (see Figure 4 on page 79) and I developed those concepts into the substantive grounded theory.

As stated by Charmaz (1990, p. 1170), using grounded theory method to study a chronic condition provides the researcher with strategies to conceptualise large amounts of data and then ‘move the emergent conceptualizations towards more general theoretical statements’. In this way, these theoretical statements provide a deeper understanding of the experience of living with a chronic condition as well as contributing new knowledge to the discipline (Charmaz 1990).

4.13 Rigour in grounded theory studies

In research, rigour refers to the scrupulous attention to detail that occurs throughout the research project. The attention to detail allows others to scrutinise the methodological accuracy thereby enabling them to determine whether or not the research results can be ‘trusted’ (Taylor, Kermode & Roberts 2006). Charmaz (2014) suggested four criteria for evaluating the rigour of grounded theory studies; credibility, originality, resonance, and usefulness. These four criteria need to be applied in accordance with the purpose and context of the research (Charmaz 2006; Birks & Mills 2011). Charmaz (2006; 2014) indicated credibility and originality of the research produces resonance and usefulness and the value of the contribution to the discipline. Charmaz (2014, pp. 337- 338) provided a list of questions under the four criteria she recommended for evaluating grounded theory. I have included several of Charmaz's recommendations for rigour throughout the following discussion and they are shown in italics (see 4.13.1 – 4.13.4 on pages 74 - 75).

4.13.1 Credibility

Charmaz (2006) suggested the 'relevance, substance, scope and depth' of the data determines the credibility of the study. My *intimate familiarity with this topic* through my previous knowledge and experience, the inclusion of reviewed literature and the systematic analysis of the data, all demonstrate credibility of the current research. The inclusion of a discussion on theoretical saturation (see 4.10 on page 71) indicates that *sufficient data* were present *to warrant the claims* of the study. The use of constant comparison of the data and memos demonstrate *systematic comparisons* between the data and the categories. *Strong links between the data* and my *arguments and analysis* are demonstrated in the thesis by using constant comparison analysis, memo writing and diagramming. The thesis, and this chapter in particular, provides information about how the research was conducted, with supporting evidence included, which should enable *readers* of the study *to form an independent assessment* of the study. In addition, consultation with PhD supervisors was used to discuss developing categories and theory (Charmaz 2014, p. 337).

4.13.2 Originality

The originality of the theory was demonstrated throughout the thesis with the *freshness of the categories* as the data was compared with existing literature to find similarities and differences. The comparison of the categories with existing literature further advanced the findings, by supporting and building upon current ideas and practices. The study offers *new insights* because there has been no construction of theory on this phenomenon and to my knowledge no one has previously explored how the person with T1D experiences self-management in hospital. The *social and theoretical significance* is included in the final chapter, which discusses the practical implications of the study's findings and the theory is embedded throughout the findings chapters (see Chapter 6, 7 & 8 on pages 88, 138 & 178). Overall the substantive grounded theory constructed in the study does *challenge and extend current ideas, concepts and practices* (Charmaz 2014, p.337).

4.13.3 Resonance

Resonance focuses on the need for the constructed theory to have meaning and scope for those to whom it is relevant. In relation to revealing *taken for granted meanings* I made sure I clarified meanings with participants during the data generation rather than making assumptions about what they meant. My *taken for granted meaning* may have varied from the participant's meaning, so asking them to expand on or explain their meaning was important so meaning could be derived from a number of angles.

In order to demonstrate whether my constructivist *grounded theory makes sense to the participants,* I checked the conceptual model with the participants (see Figure 4 on page 79). Three participants were provided with a diagram of the conceptual model and interviewed to provide feedback on whether the conceptual model was an accurate representation of their T1D self-management experience in hospital. The three participants who were interviewed for this aspect of the study all strongly agreed the conceptual model was an accurate representation of their self-management experience. In addition, all participants were emailed a summary of the key findings and conceptual model (see Appendix 16 on page 278). Most participants (12 of the 14 who responded) indicated they had an overall sense of the model being relevant to their experience and that it captured what they said to me as the researcher. Presentations at local and national conferences and a publication also showed the content of the study resonated with people living with T1D and health professionals (Charmaz 2014, pp. 337 - 338). The resonance of presentations was indicated through positive audience feedback and appraisals from conference organisers.

4.13.4 Usefulness

Usefulness involves determining whether and how the research contributes new knowledge and how the knowledge can be applied. Charmaz (2014) asked whether the research could be *used* *every day.* People with T1D, or another chronic condition, and health professionals providing care for these people, could use the outcomes of the study every day. This study demonstrates usefulness because it can be practically applied in education, practice, policy and *further research* (see Chapter 9 on page 199). In addition, the *contribution to knowledge* the study provides is a unique perspective about people with T1D self-management experience in hospital, which has not been previously explored in the level of detail as was the case in this study (Charmaz 2014, p. 338).

Feedback from the participants about the conceptual model and explanation of findings suggested the study was useful to them. Two of the participants provided the responses below:

> *Thank you so much for caring about this and thank you for taking the time to let me know how it is going. I would love to stay in the loop if you can manage it. You are doing something, from my perspective at least, very, very valuable. I would have approached things differently if I had understood the hospital and medical staff involved in my surgery understood so little (Marie).*
>
> *I like the model you have developed - very accurate from my point of view and hope that all HCP* (health care professionals) *will take the time to read and absorb it (Laura).*

4.14 Chapter summary

Chapter four provided detail about the CGT methods used to explore the experiences of participants' T1D self-management in hospital. The use of these specific methods enabled the core tenets of CGT to be met and the construction of the substantive grounded theory for this phenomenon, *Keeping Self Safe.* In addition, the chapter provides an audit trail of how the study was conducted. The substantive grounded theory constructed in the study will be presented in the following four chapters. Chapter five will provide an introduction to the substantive grounded theory and the conceptual model and will introduce the people living with T1D who participated in the study.

Chapter Five: The grounded theory

5.1 Chapter overview

Chapter four focused on the generation and analysis of the data that was guided by Charmaz's constructivist grounded theory (CGT) methods. The study used CGT methods informed by a social constructionist and symbolic interactionist perspective in order to interpret the experiences of the participants. Through the use of the core tenets of CGT method a substantive grounded theory was constructed that explained the way people with type 1 diabetes (T1D) experience self-management in hospital in the particular the context in which they experienced it. Chapter five provides a brief introduction to the substantive grounded theory, *The Social Construction of Keeping Self Safe*, along with the conceptual model developed to depict and explain the theory. Chapter five also introduces the 14 people living with T1D who participated in the co-construction of knowledge for the study. The introduction of the participants provides the context for their most recent self-management experience of their T1D in hospital. While the term participant is used throughout the findings chapters, it is important to acknowledge that these participants are people living with T1D every day therefore they are much more than just participants in the study.

Chapter five is the first of four findings chapters presented in the thesis. Chapters six and seven describe the actions and meanings the participants with T1D used to socially construct their self-management experience in hospital that underpins the construction of the substantive grounded theory presented in Chapter eight. The decision to divide the findings into four separate chapters was to enhance the readability of the thesis. However, the experience of the participants was not necessarily linear and there were overlaps in their experiences across the concepts discussed in these chapters that influenced their self-management.

5.2 The substantive grounded theory

As stated in the chapter overview, the substantive grounded theory constructed during this study was *The Social Construction of Keeping Self Safe*. This substantive grounded theory was developed from the experiences of the participants who had recently been admitted to hospital for a primary admission diagnosis other than T1D and their perspective on their T1D self-management while in hospital. This theory provides insight into the social processes that influenced the participants' experiences of self-management of T1D in hospital. *The Social Construction of Keeping Self Safe* will be discussed in detail in Chapter eight and is presented as a conceptual model in the following section (see 5.3 and Figure 4 on page 79).

5.3 The conceptual model

The conceptual model was developed to provide a visual representation of the abstract ideas that account for the data generated in the study (Charmaz 2014). Charmaz (2014, p. 342) suggested the 'concepts provide' an 'abstract understanding of the studied phenomenon', which the researcher constructs and then demonstrates how these concepts are grounded within the data they collected and how they relate to each other. In the conceptual model (see Figure 4 on page 79), the concepts are the categories, which are unidirectional and interact with each other leading to the core category of *Keeping Self Safe*. The conceptual model is a diagrammatic representation of the categories, and the core category, which emerged from the analysis of the participants' data of their experience of T1D self-management in hospital.

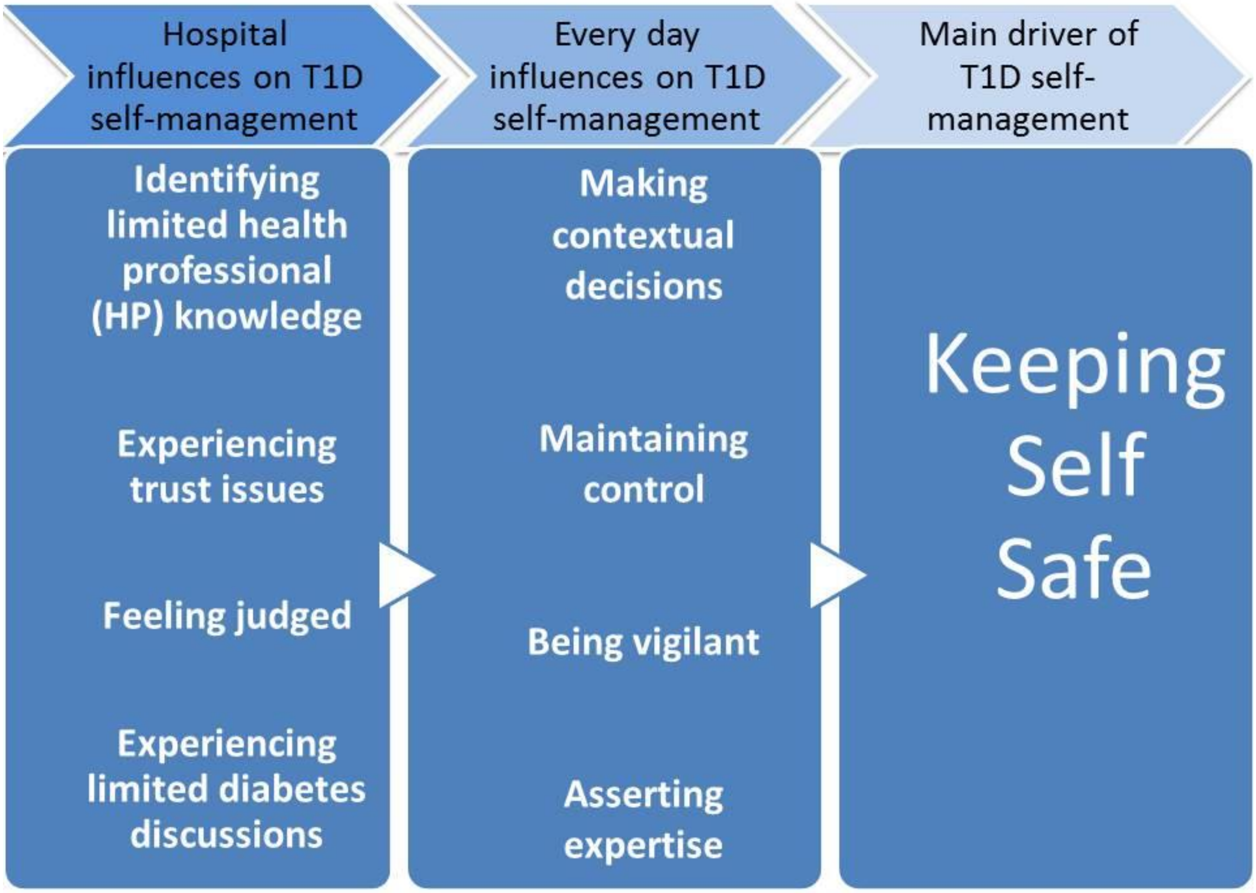

Figure 4: Conceptual model of the substantive grounded theory *Keeping Self Safe*

5.3.1 Hospital influences on T1D self-management

The first component of the model encompasses the external influences that impacted the participants' self-management in hospital. These external influences impacted the participants' actions and the meanings they gave to their interactions with health professionals that were directly related to their T1D self-management. The categories relating to specific hospital influences are *identifying limited health professional knowledge* about self-management of T1D, *experiencing trust issues* with the health professionals to provide appropriate care, the participants *feeling judged* by the health professional around self-management of their T1D and *experiencing limited diabetes discussions* with health professionals. The direction of the arrows from this component of the conceptual model shows the relationship between the external hospital influences and the actions of the participants in response to their experience of self-managing their T1D in hospital.

5.3.2 Everyday influences on T1D self-management

The second component of the conceptual model identifies the internal influences participants with T1D relied on to effectively self-manage their T1D in hospital. Participants relied on and applied the knowledge and skills they had developed to self-manage their T1D each day outside of the hospital, in response to external influences in the hospital (see 5.3.1 on page 79). The categories relating to specific everyday influences are *making contextual decisions* around self-management, *maintaining control* of their chronic condition, *being vigilant* in response to threats to their T1D management and *asserting expertise* based on their experiential knowledge of their T1D. The direction of the arrow from this component of the conceptual model demonstrates the everyday influences that lead to the main internal driver of all the actions and decisions about self-management of T1D in hospital, which is the core category of *Keeping Self Safe*.

5.3.3 Main driver of T1D self-management

The core category, *Keeping Self Safe*, was central to explaining the participants' experience in relation to T1D self-management in hospital. Each category within the hospital influences compelled the participants to rely on their everyday self-management construction while in hospital in order to keep themselves safe and prevent themselves from being harmed by health professionals during their admission.

5.4 Participants

In total, twelve women and two men living with T1D participated in the study. All participants shared their most recent experience of self-management of their T1D while in hospital. The focus group was conducted with five participants (see Table 2 on page 81). Ten people with T1D participated in the in-depth interviews (see Table 3 on page 83). One participant (Trish) was interviewed three times about three separate hospitalisations for different admission diagnoses. In addition to the 12 in-depth interviews, three follow up interviews were conducted (Lucy, Nicola and Dave). The data were de-identified and pseudonyms allocated to protect the confidentiality of each participant, as discussed in Chapter four (see 4.3.3 on page 57).

5.4.1 Focus group participants

All participants in the focus group were asked five demographic questions. These included questions about their gender, current age and age at T1D diagnosis, insulin delivery method and the reason for their most recent hospitalisation (see Table 2 on page 81). There was no need to collect further demographic data from these participants because the purpose of the focus group was to inform the in-depth interview questions. All of the participants were from South Australia (SA), and were recruited from a Diabetes SA refresher day as detailed in Chapter four (see 4.4 on page 58). The focus group was conducted in SA with only SA residents as a result of the researcher being located in SA and the requirement to conduct the focus group in person.

Table 2: Focus group participants

Pseudonym	Gender	Age	Life stage at diagnosis	Insulin delivery method	Planned or emergency admission	Admission diagnosis
James	M	59 - 68	Childhood	Pen	Planned	Surgical procedure
Lisa	F	29 - 38	Childhood	Pen	Planned	Surgical procedure
Susan	F	59 - 68	Childhood	Pen	Planned	Surgical procedure
Jane	F	59 - 68	Adulthood	Pump	Planned	Medical admission
Trish *	F	29 - 38	Childhood	Pump	Emergency	Medical admission

*Trish was also a participant in the in-depth interviews

Pen - insulin pens are used for administering insulin using multi daily injections (MDI). MDI requires the use of intermediate or long acting insulin injected at least once and sometimes twice each day along with rapid or short acting insulin to be injected with meals (Visekruna, Edge & Keeping-Burke 2015).

Pump - continuous subcutaneous insulin infusion (CSII) or insulin pump therapy (IPT) is used to deliver insulin. While CSII is the correct medical terminology the participants who used this insulin delivery method referred to CSII or IPT as a pump. Therefore, throughout the findings chapters CSII or IPT will be referred to as a pump to reflect the language used by the participants. The participants who used a pump for their insulin delivery used a rapid acting insulin, which is the type of insulin required for pump use (Visekruna, Edge & Keeping-Burke 2015; Diabetes Australia 2015b).

5.4.2 In-depth interview participants

All participants who participated in the in-depth interviews were asked a number of demographic questions in order to contextualise their diabetes history and their most recent hospital admission (see Table 3 on page 83 & Table 4 on page 84).

Table 3: In-depth interview participants

Interview number & Pseudonym	Gender	Age	Education level	Location	Age at T1D diagnosis	Insulin delivery method	BGL/ day	HbA1c (% and mmol/mol)#	Admission type
1, 13. Lucy**	F	66	University	Victoria	15	Pump	4-6 CGM	7.1% 54 mmol/mol	Planned
2. Clare	F	45	High School	SA	3	Pump	10 - 12	7.9% 64 mmol/mol	Planned
3. Kate	F	43	High School	QLD	13	Pump	4	7.8% 62 mmol/mol	Planned
4, 14. Nicola**	F	44	University	NSW	14	Pump	5	7.4% 57 mmol/mol	Planned
5,7,8. Trish*	F	45	University	SA	10	Pump	2 CGM	6.8% 51 mmol/mol	Emergency, Planned, Emergency
6. Laura	F	60	University	Victoria	10	Pen	4	7.8% 62 mmol/mol	Planned
9. Eve	F	31	University	Victoria	23	Pump	3 CGM	6.2% 44 mmol/mol	Planned
10. Bianca	F	26	TAFE	Victoria	6	Pump	6	7.3% 56 mmol/mol	Planned
11, 15. Dave**	M	57	University	Victoria	14	Pen	1 CGM****	6.2% 44 mmol/mol	Emergency
12. Marie	F	48	TAFE***	NSW	14	Pump	10 - 12	5.8% 40 mmol/mol	Planned

***** Trish participated in the Focus Group and was interviewed three times with three separate hospital admissions for different admission diagnosis

** Follow up interview undertaken with participant to discuss and verify conceptual model

*** TAFE is a vocational education and training course provider in Australia

****CGM – Continuous glucose monitoring with the BGL /day used for calibration of CGM device

States of Australia- South Australia (SA), New South Wales (NSW) and Queensland (QLD)

HbA1c levels reported in old (%) and new units (mmol/mol) of measure because participants used the old measure when they self-reported their most recent HbA1c.

Table 4: Length of stay for in-depth interview participants

Overnight	**1 – 2 day**	**3 – 4 day**	**5 – 6 day**	**7 – 8 days**	**10 days or above**
2	3	3	1	1	2

In-depth interview participants were aged between 3 and 23 years when diagnosed with T1D; seven participants were diagnosed between the ages of 10 – 15 years. According to Diabetes Australia (2015), the onset of T1D has generally occurred most frequently in people under the age of 30 and this fits with the study's participant profile. However, Diabetes Australia (2015) suggested recently that almost half of people newly diagnosed with T1D are older than the age of 30 years. When considering age of diagnosis and the current age of the participants, they had all lived with T1D for a minimum of eight years with eight participants having lived with T1D for a minimum of 30 years. These data indicate that the majority of participants had an extensive opportunity to develop expertise in self-managing their T1D over time that they could rely upon while in hospital (Paterson & Thorne 2000[8]; Ingadottir & Halldorsdottir 2008).

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[8] Paterson and Thorne (2000) identified one measure of expertise as having lived with T1D for a minimum of 15 years

The number of blood glucose levels (BGLs) participants performed each day at home varied, regardless of whether they used continuous glucose monitoring (CGM) or capillary blood glucose monitoring (BGM).[9] The participants using CGM, monitored their BGL between one and six times per day for the purpose of calibrating the CGM and for quality assurance (Visekruna, Edge & Keeping-Burke 2015). Participants who used capillary BGM reported monitoring their BGL between four and 12 times per day. All participants without a CGM indicated that the number of BGLs undertaken each day could vary depending on factors that influence their BGL such as illness, which can increase BGL, or varied levels of activity, which can lead to either an increase or decrease of BGL depending on the activity.

A clinical measurement frequently used in studies that include people living with diabetes is HbA1c, known as glycated haemoglobin or glycosylated haemoglobin. As the red blood cell is known to live for approximately 120 days the HbA1c measures the amount of glucose that has attached to the red blood cell in that time, which provides an average plasma BGL over the previous 120 days (Phillips 2012). In Australia, the recommended HbA1c for an individual living with T1D is 6.5% (48 mmol/mol) to 7% (53 mmol/mol). The participants in the current study self-reported their most recent HbA1c levels were between 5.8% (40 mmol/mol) and 7.9% (63 mmol/mol), which they felt was within their individualised target range.

All participants reported they had a variety of concurrent chronic conditions in addition to their T1D, which included Multiple Sclerosis, Hashimoto's disease, Osteomyelitis, gynaecological conditions and Asthma. Nine of the ten interview participants took one or more medications in addition to their insulin every day to manage their other chronic conditions. Some of the surgeries participants had previously been admitted to hospital for included cataract surgery, total knee replacement and laparoscopies.

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[9] A CGM is a device which provides the person with T1D with continuous interstitial fluid glucose levels via a small sensor inserted subcutaneously (Visekruna, Edge & Keeping-Burke 2015).

The opportunity for involvement in a pre-admission appointment varied for the participants who experienced a planned admission to hospital. Of the nine planned hospital admissions, five participants attended a pre-admission appointment, either in person or remotely over the phone or online, and four participants were not offered a pre-admission appointment. Of the five participants who had some form of pre-admission appointment, one participant had a discussion about their diabetes management while in hospital during the pre-admission appointment, while another participant in an online pre-admission appointment was asked only what medication they took in relation to their diabetes management. Four participants who had a pre-admission appointment indicated that the focus of the pre-admission appointment was on their primary admission diagnosis, which has previously been identified in the literature as an issue for people with chronic conditions being admitted into hospital (Williams 2004; Anthony 2007; Cohen et al 2007).

5.5 Findings chapters

As stated in the chapter's overview, Chapter five is the first of four findings chapters. Chapter five introduced the substantive grounded theory, the conceptual model and established the context of the participants in the study. The following three findings chapters focus on each specific component of the conceptual model.

Chapter six, *Hospital influences on T1D self-management*, focuses on the external influences in hospital that directly impact on T1D self-management and demonstrates how these external influences affect and shape the way participants construct their self-management.

Chapter seven, *Everyday influences on T1D self-management*, discusses the internal influences people with T1D engage in every day to self-manage their T1D. The chapter demonstrates how and why participants rely on these every day influences in hospital based on how they constructed their T1D self-management.

Chapter eight presents the substantive grounded theory, *The Social Construction of Keeping Self Safe,* which is central to actions a person with T1D performs in hospital in relation to their self-management. The mechanism to protect themselves from harm and to keep their diabetes within target ranges, comes from years of contextual experience and the use of their expert knowledge.

5.6 Chapter summary

Chapter five described the first of four findings chapters included in this thesis. The people living with T1D who participated in the study were introduced and some context to their episode of hospitalisation was provided. The substantive grounded theory and the conceptual model were also introduced. In addition, the chapter outlined the focus of each of the following three findings chapters using the conceptual model structure. Chapter six will focus on the first component of the substantive grounded theory from the conceptual model; *Hospital influences on T1D self-management*, which includes *identifying limited health professional knowledge*, *experiencing trust issues*, *feeling judged* and *experiencing limited diabetes discussions*.

Chapter Six: Hospital influences on T1D self-management

6.1 Chapter Overview

Chapter five introduced the conceptual model and presented an overview of the substantive grounded theory specific to the experience of self-management in hospital for the person with type 1 diabetes (T1D). In addition, Chapter five introduced the people living with T1D who participated in the study and provided their demographic information. Chapter six presents four main categories generated from the data that are unique to the participants' experience of being in hospital. These categories are external to the people with T1D who participated in the study and were found to have an influence on the participants' construction of self-management in hospital. These categories are; *identifying limited health professional knowledge, experiencing trust issues*, *feeling judged* and *experiencing limited diabetes interactions* (see Figure 4 on page 89). The health professionals referred to throughout the findings chapters are generalist health professionals for example a nurse on a surgical ward. Health professionals referred to with diabetes expertise have their designated profession named, for example Endocrinologist. Chapter six examines the way these external influences, occurring in hospital, are situated within the substantive grounded theory of *Keeping Self Safe.*

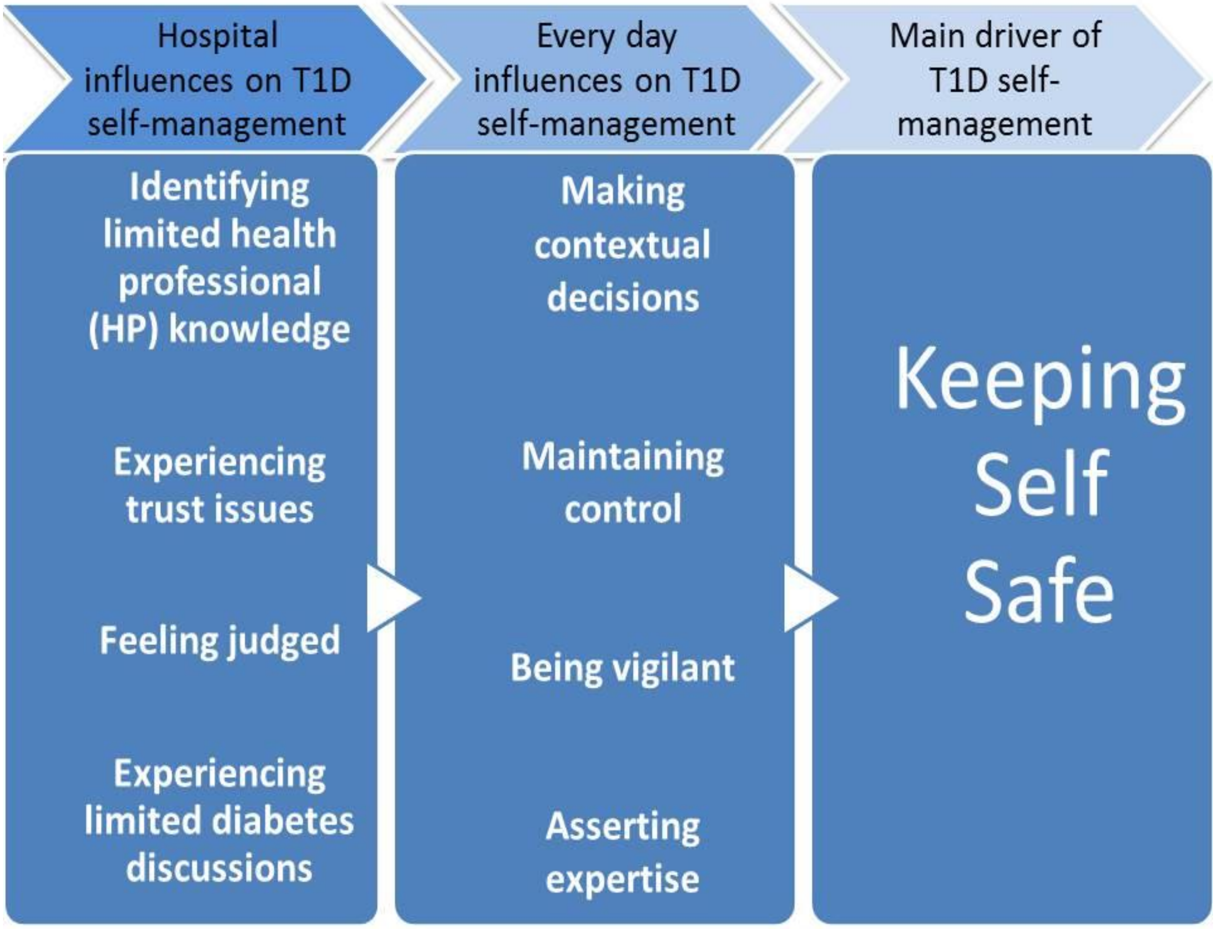

Figure 4: Conceptual model of the substantive grounded theory *Keeping Self Safe*

6.2 Identifying limited health professional knowledge

The first category generated from hospital influences on T1D self-management was *identifying limited health professional knowledge.* Knowledge itself was defined as an:

> '….awareness, understanding, or information that has been obtained by experience or study, and that is either in a person's mind or possessed by people generally' (Cambridge Dictionary 2019).

In most cases, health professionals have obtained knowledge specific to their role through formal study and clinical experience. Traditionally, health professionals' knowledge is often viewed as authoritative because their knowledge was socially constructed as being both legitimate and dominant (Jordon 1997). Consequently, those who have knowledge that is considered to be outside the conventional understanding of knowledge such as those with a lived experience of T1D, may be viewed as having inferior knowledge. Regardless of whether knowledge is viewed as legitimate or inferior, both constructs reflect the usual power differentials that exist between health professionals and patients in healthcare (Jordon 1997). Jordon (1997, p. 56) stated ‘the devaluation of non-authoritative knowledge systems is a general mechanism by which hierarchical knowledge structures are generated and displayed’. What Jordon’s quote suggests is that, within the hierarchical hospital system, the health professional is seen to hold authoritative knowledge while the patient is seen to have the non-authoritative knowledge. However, the preliminary literature review for the current study found that, in many cases, generalist health professionals in hospitals have limited knowledge of diabetes management while the person with T1D has expert knowledge about their condition (see 2. 7 & 2.8 on pages 26 & 30).Therefore, these findings challenge the usual constructions of what is considered to be authoritative knowledge as well as who is the bearer of such knowledge.

As previously described in Chapter two (see 2.7 on page 26) the majority of studies conducted to ascertain health professionals’ knowledge about diabetes predominately used quantitative data and all suggest health professionals need further education to improve their knowledge about diabetes. However, these studies have not sought to explore or recognise the impact these knowledge deficits may have on the person with T1D in hospital and the risk of harm posed to these patients as a result of these known knowledge deficits. The perspectives of the participants in the current study regarding health professionals’ knowledge of their diabetes offer a unique insight into how T1D self-management is socially constructed in hospital.

6.2.1 Overall knowledge deficit

Identifying limited health professional knowledge occurred in two ways by the participants in the study; health professionals’ general knowledge of T1D as a chronic condition and their misunderstanding of the complexity of T1D self-management. The participants believed that the health professionals they interacted with in hospital had an overall limited understanding of T1D. This belief developed through previous interactions with health professionals in a variety of settings, including during previous hospital admissions. While there was consensus amongst the participants that health professionals have sufficient knowledge in certain areas of health care, there was agreement that health professionals did not have sufficient understanding of T1D or T1D self-management and lacked awareness of what T1D self-management means to people with T1D. Eve summised:

> *….no matter how much they've been to medical school or whatever, I just don't think they grasp the full extent of the condition (Eve Interview (Int.) 9).*

In addition, the participants felt that health professionals did not consider the uniqueness of each person's experience of living with T1D and how their self-management needs varied. Clare captured this agreed understanding when she stated:

> *I mean I know like nurses and doctors are medical people but they're trained in either specific fields or very general fields, not necessarily me and my diabetes (Clare Int. 2).*

Conrad and Barker (2010) suggested that the construction of illness for health professionals comes from the medical model, which makes the assumption that diseases are universal and invariant to time and place. Such a construction of illness reinforces the assumption often held by health professionals that all people living with T1D have the same 'disease', so the management of their chronic condition and the response to the management will be the same. Trish and Marie both identified the individuality of people living with T1D. Marie made the point that such individuality can present a challenge for health professionals.

> *….I really think that everyone's type 1 diabetes is so different. Talking to people, it's becoming very obvious that everyone is so different and so individualised in what works for them. So, I think that's another problem for the health professionals as well (Marie Int. 12).*

> *…. people with diabetes, especially with type 1, you could line us all up in a room together and we won't ever fit the bill cause you could give us all 5 units of insulin and we would all do something completely different (Trish Focus Group (FG)).*

On the other hand, the way illness is socially constructed is also grounded in the experiences of those living with illness (chronic conditions). Hence, 'illnesses have both a biomedical and experiential dimension' (Conrad and Barker 2010, p. S69) so health professionals and those living with illness (chronic condition) may have very different understandings of what it means to live with and manage T1D. Trish highlighted some of these differences when she said:

> *I believe it* (understanding of T1D) *has a lot to do with the fact that they* (health professionals) *think that they know what's best because they're medically trained. They*

> *have no consideration whatsoever for the fact that type 1 is an individual disease, and they just think, 'well this is what we learnt at Uni, and you must fit that box'. I've had to learn very quickly that just because a text book says that, doesn't mean that my body's going to agree (Trish Int. 5).*

For many participants, the recognition that health professionals did not have specific knowledge about the unique aspects and impacts of their T1D led them to believe they were the 'best person' to manage their T1D in hospital. For example Clare stated:

> *I think I'm the best person for it* (T1D management). *I'm the one who knows my body. I know my diabetes. I know the kit* (diabetes equipment), *so yeah (Clare Int. 2).*

The belief that health professionals have limited knowledge was developed by the participants through their interactions with health professionals in hospital during their most recent hospitalisation and during previous episodes in hospital. Limited health professional knowledge became evident to the participants through the health professionals' actions about specific diabetes management tasks and as a result of discussions they had with health professionals around the requirements of T1DM management. Nicola captured this belief when she stated;

> *Going into hospital makes me really nervous…..because I know that the nurses and the doctors have got no idea about my condition. When people mention the word type 1 diabetes, they freak out….I think it's because of their lack of understanding, they shy away from it, it makes them uncomfortable (Nicola Int. 4).*

While Nicola stated health professionals have a limited knowledge of T1D management, she believed the lack of knowledge makes the health professional feel uncomfortable around patients with T1D. However, the result of being aware of the knowledge deficit about T1D led Nicola to feel frightened about the consequences of her diabetes being managed by health professionals with a poor understanding of T1D management. She stated:

> *To know that generally the people who are looking after us don't have any idea of our medical condition and how to manage that when we're unable to do so, is really quite frightening (Nicola Int. 4).*

6.2.2 Specific self-management knowledge deficits

While the study participants identified an overall misunderstanding of T1D by health professionals, they additionally recognised health professionals lacked knowledge about specific T1D self-management tasks. These identified knowledge deficits were predominantly around dietary management and insulin administration.

6.2.2.1 Dietary management

The participants felt health professionals in hospital misunderstood the informed choices a person with T1D makes in relation to their dietary intake. Participants believed health professionals did not understand the role diet played in their self-management, nor the use of their contextual decision-making (see 7.2 on page 139) the participants relied upon to make their food choices. Use of contextual decision-making meant that participants were making the best and most appropriate choices for themselves given their situation at the time. However, they experienced health professionals judging their food choice as inappropriate. For Trish, making an informed choice about her dietary intake in hospital was important to her, especially when she felt the health professional was making ill-informed decisions about her dietary intake. Trish said:

> *If I choose to eat sugar and then manage that on my insulin pump while I'm in hospital, that's my choice to make. I will not be dictated to by someone who has absolutely no understanding of my condition as to what I choose to eat or not eat (Trish Int. 5).*

Similarly, Eve felt her dietary knowledge, as a component of her usual self-management, was being dismissed by health professionals during her time in hospital. Moreover, the health professionals were overriding her choices and choosing meals that were not appropriate for her to safely manage her T1D. Eve was making choices to remain safe in hospital but she believed her choices were being dismissed and undermined by health professionals who did not involve Eve in their decision-making. Eve stated:

> *I was just choosing food that I would normally eat. I wasn't choosing juices or anything outrageous and they changed my menu, like they overrode it and wrote diabetic meals only and just delivered like low carbohydrate food which is irrelevant to me because especially if I've had, maybe if I'm a bit low before a meal I'll actually want a carbohydrate meal…It was*

> *almost just saying for me, oh you don't know, here eat this. But I was actually like, no, that's not how it goes (Eve Int. 9).*

Eve perceived the health professionals did not understand her requirement for complex carbohydrates at meal times. The actions of the health professional left Eve at potential risk of experiencing hypoglycaemia as a result of having insufficient carbohydrate available for her meal. Flanagan et al (2018) supported people with diabetes in hospital being able to make their own food choices from the menu. Once again, health professionals may not have sufficient or appropriate knowledge to understand the nuanced decision-making of the person with T1D around healthy food choices and may question the capability of the person with T1D to make appropriate food choices, particularly if the food chosen is considered to be inappropriate for a person with diabetes.

The majority of people with T1D have consulted a dietitian for dietary advice at some point since their diagnosis. In addition, people with T1D may have undertaken further intensive training such as carbohydrate counting if they use a pump or if they have been involved in a Dose Adjustment for Normal Eating (DAFNE) program (McIntyre et al 2010). Therefore, the level of knowledge the person with T1D has about healthy food choices and the carbohydrate content of food is highly likely to be more advanced than that of the general health professional especially if the person with T1D is on a pump.

6.2.2.2 Insulin management

Participants in the current study identified health professionals had a limited understanding about insulin, which people with T1D administer every day at home. This perceived limited understanding included knowledge deficits about the action of insulin, the type of insulin needed and the correct storage of insulin. All types of insulin have been identified in Australia as high-risk medicines (ACSQHC 2019) and a national subcutaneous insulin chart was developed (ACSQHC 2019a) was developed in order to reduce the risk of insulin error for people in Australian hospitals. However, despite the risks around insulin use in hospitals being identified nationally, participants found that such knowledge deficits continue to exist and this caused them concern.

Lisa felt concerned that the health professionals she was discussing her insulin administration with had a limited understanding of the particular type of insulin she had been prescribed. She said:

> *I've just found when I go and see my surgeon….I say 'I'm on this insulin and that insulin' and he looks at you and goes 'what?' like he has no idea how the profile of the insulin works so that I find amazing. Then when I see the anaesthetist on the actual day of the surgery and he's asking you questions about your diabetes and 'I'm on this insulin' and he goes 'what?' and you think great people don't even know the action or the profile of how the insulin works so I find that frustrating….so it's just the staff don't know the profile of that insulin or have never even heard of the insulin. I use Levimir which is not a widely used insulin, it is mainly used for type 1s, and I always use* (say) *Detemir, which is its correct term, and they go 'who' and I say' Levimer' , 'uhh?', and you think great so I am dealing with staff that don't even know my insulin (Lisa FG).*

Similarly, James experienced a limited understanding from a health professional in hospital about the type of insulin he self-administered at home. The health professional wanted to administer incorrect insulin to him based on a misunderstanding that Actrapid (short acting insulin) and Novorapid (rapid acting insulin) have the same action. James was able to articulate that he did not want the incorrect insulin and that he would self-administer his own correct insulin.

> *They* (the nurse) *brought their own insulin and they said 'we don't have Novorapid, we've got Actrapid'. I said 'Actrapid is not the same as Novorapid'. 'Oh it's the same' they said and I said 'forget it' (James FG).*

Lisa offered her opinion on a health professionals' misunderstanding of the actions of Novorapid and Actrapid by stating:

> *….because most hospitals work with Actrapid when you say 'Novorapid' they think it works the same way as Actrapid. No, it has a different response time all together (Lisa FG).*

Flanagan et al (2018) recognised that people who have T1D will have a greater knowledge of their insulin regime than the health professionals working in hospital. Participants in the study recognised the health professionals they interacted with in hospitals had a limited understanding of the different types and differing actions of insulin and the influences these differences had BGLs. These participants self-reported they were well aware of the type of insulin they were prescribed, the action of the insulin and how to determine the dose of insulin required, along with the anticipated outcome of administering their insulin. Flanagan et al (2018) and Taylor et al (2018) found that health professionals' errors with insulin administration is a problem in hospitals and can have negative consequences for the person with T1D, including placing the person at risk of adverse health outcomes such as hypoglycaemia. Flanagan et al (2018) indicated a key strategy to improve the safety of insulin administration in hospital is to allow the person with diabetes who has the appropriate skills to self-manage their insulin.

Some participants had heard 'horror stories' from other people with T1D experiences in hospital that made them realise some health professionals did not have an adequate understanding of the requirements and timing of insulin administration. This finding suggests that expectations of hospitalisation, and the associated fears arising from such expectations, can be constructed through interactions with others within the T1D community and their experiences. Clare stated:

> *I hear these nightmare stories where they take your insulin off you and only bring it when they feel like it and yeah it's just oh horror stories (Clare Int. 2).*

Being aware that health professionals have taken equipment away from other people with T1D in hospital led Clare to feel grateful for having a pump, so she could be assured of the accurate administration of her insulin.

> *….but the time I was the most grateful to have it* (pump) *was when I ended up in hospital. If I hadn't been on the pump oh my goodness I don't know* (what would have happened) *(Clare Int. 2).*

The participants using pumps were unintentionally given full responsibility for managing their insulin administration in hospital because the health professionals suggested they did not have the requisite knowledge, understanding or confidence to become involved with the patients' pump management. Participants stated:

> *I sort of got the impression they didn't know much about the pump so they just left it to me (Bianca Int.10).*
>
> *They don't know what to do with the pump and even the Doctor in emergency last time said 'well you will manage that yourself?', I wasn't asked I was sort of told. 'You do know what you're doing don't you? Please don't say no!'…. I think they are scared of the pump to be honest (Jane FG).*

While Trish was not expecting health professionals to physically manage the pump on her behalf, she believed they should at least have an understanding of the function of the insulin pump. Furthermore, she felt concerned that the health professionals were choosing to *ignore* learning about the pump and making the choice to *ignore* the fact that she had a pump to deliver her insulin.

> *They're not expecting to button push, I understand that. But a fundamental understanding of what an insulin pump does is crucial….I have enormous concerns that to just go, 'oh well, I don't understand what it does, therefore I'm going to ignore it' (Trish Int. 5).*

Bianca self-managed her pump because she did not want health professionals with a limited understanding of and exposure to pumps having any responsibility for managing it on her behalf.

> *….I've had a lot of hospital admissions where nurses say oh, 'we've never seen a pump before' or 'we don't know anything about that' or, so you just sort of get used to doing it yourself because you don't want people that don't know what they're doing touching your pump (Bianca Int. 10).*

Bianca also felt there was limited understanding of how the pump functioned. She believed some health professionals erroneously believed that the person with T1D was not required to undertake any self-management with a pump, as it was an automated insulin delivery. However, she did acknowledge that there seemed to be an overall slow improvement in health professionals' understanding of pumps during her most recent hospitalisation. Bianca stated:

> *I don't think they* (health professionals) *have a great understanding of that* (insulin pump function). *I think - a lot of people* (health professionals) *seem to think that you don't have to touch the pump and it just does everything itself. That's the impression I seem to get a lot of the time…. I think there's definitely a lack of knowledge around pumps but I think it is slowly getting better (Bianca Int. 10).*

6.2.3 Recognising difficulties for health professionals

Some participants demonstrated an insight into the difficulties health professionals faced when providing care for a patient with T1D. Dave questioned whether health professionals' lack of knowledge stemmed from *their limited experience in interacting with engaged*[10] *people* with T1D (Dave Int. 15). Other participants expressed sympathy towards health professionals in relation to

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[10] Dave described people engaged in their T1D were actively involved in their self-management

the requirement that they had to know so much about everything. Clare specifically acknowledged this requirement of nurses.

> *…..my goodness those nurses, you have to take so much in and know so much about everything and that's just one more thing to have to know about - or have access to the information somehow, somewhere (Clare Int. 2).*

Similarly, Eve acknowledged the difficulties health professionals faced having to know about *everything* but suggested they needed more *awareness and respect* for T1D (Eve Int. 9).

> *It would just be great if they had a bit more understanding. I guess they can't know everything about every condition, but yeah, just knowing a few more of the ins and outs of things would be great. I mean I'm always happy if someone asks me something, I'm always happy to let them know or educate them on whatever, but just - even if they don't know everything that's fine, but maybe a little bit more sort of awareness and respect for it* (T1D) *(Eve Int. 9).*

As a result of recognising the limited knowledge of self-management technology, some of the participants chose to educate health professionals. Rasmussen, Wellard and Nankervis (2001) similarly found that participants in their study identified nurses as having poor knowledge of diabetes and as a consequence they took on board the role of educating the health professional. In the current study Nicola and Trish provided education to health professionals about continuous glucose monitoring (CGM) with Nicola stating:

> *….just because you are a health professional it doesn't mean you can't learn from your patients (Nicola Int. 12).*

Likewise, Clare provided education to those nurses who expressed an interest in her pump and she felt comfortable and equipped to take on this teaching role by saying:

> *They were all so interested in my pump. They'd heard about them but they didn't know anything about them, so everybody, you know, all the nurses from other wards were coming 'ooh I've heard you're on a pump, let's have a look', 'can we have a look and can you tell us about it?' (Clare Int. 2).*
>
> *….you know it felt to me that it was something they should know about and I'm so happy to spread awareness and that. I was like, I was in my element, like yes it does this and it does this and it's wonderful (Clare Int. 2).*

Participants were also aware that when they informed some of the nurses they would continue to self-manage in hospital, they sensed the nurses’ relief because this meant there was one less thing they had to do. The participants also sensed that the nurses’ relief was also due to not having the underlying knowledge to manage T1D in hospital, that is, if a patient continued to self-manage, their lack of knowledge would be less likely to be exposed. Marie suspected she was able to self-manage her T1D after her surgery, not because there had been any discussion prior to her surgery around her T1D management post-operatively, but by default as she felt the health professionals were overwhelmed by her chronic condition requirements of a pump and 10 – 12 BGLs a day.

> *They were happy to do that* (allow T1D self-management), *I think. Just for another reason. I think they feel overwhelmed….but I felt like they saw it* (TID) *as an extra thing they had to deal with* (diabetes management) *and if I was happy to take it on board, leave it to me. (Marie Int. 12).*

Similarly, Dave perceived the nurses’ relief at not having to manage his T1D, but he also experienced some nurses actively seeking information from him about how he usually managed his T1D.He said:

> *….they look relieved that they don't have to do it* (diabetes management) *because…. it's less for them to do. But then they come back at a later stage and go ‘can you tell me how that actually works?’ (Dave Int. 11).*

A number of the participants identified a contributing factor to the misunderstanding of T1D management was health professionals not recognising the differences between T1D and T2D. They thought this misunderstanding could be a direct result of health professionals having contact with more patients with T2D than T1D. Lisa explained:

> *I personally think because there are so many more people out there with type 2 that hospitals accommodate for type 2 and don’t accommodate for type 1 unless you are a child in a child’s hospital then yes you do get attended to, looked at as a type 1, you know treated like a person with type 1, but if you are in a hospital for adults then generally it’s type 2 that you are seeing in there so the hospital seems to accommodate for type 2 that’s what I feel (Lisa FG).*

Similarly Lucy believed:

> *They* (health professionals) *hear the word diabetes and immediately think type 2. They don't take any notice of how long you have had it or how much knowledge you have (Lucy Int. 13).*

Overall, participants believed a lack of knowledge of T1D exists amongst the health professionals they encountered in hospital. As a direct result of the participants' beliefs they acknowledged three main issues occurred in hospital. These issues were:

1. some health professionals were not able to be trusted when it came to T1D management,
2. some health professionals unfairly judged the participants T1D self-management and,
3. limited discussions around T1D occurred because health some professionals don't have the necessary knowledge to participate in a discussion.

Therefore, the external influences on the participants' construction of their T1D self-management in hospital predominately centred on the perceived limited health professional knowledge, which led to *experiencing trust issues*, *feeling judged* and *experiencing limited diabetes interactions* (see Figure 4 on page 89).

6.3 Experiencing trust issues

According to Weber and Carter (2003) trust as a social construct can be defined in many ways. However, they offer the following definition of trust as:

> '….a socially constructed orientation between two people that is premised on the belief that the other will take one's perspective into account when decision-making and will not act in ways that violate the moral standards of the relationship' (Weber & Carter 2003, p. 19).

Trust has long been associated with the role it plays in the relationship between health professionals and patients (Brennan et al 2013). Larsson et al (2007) suggested trust is the key component of the health professional-patient relationship. Birkhäuer et al (2017) suggested patients need to be able to trust that health professionals are working to meet their best interests along with seeking to achieve the best health outcomes. In addition, trust is essential for collaboration to occur between the health professional and patient in consumer-centred care

(Jones 2015). Trust in the health professional is, therefore, seen as fundamental to consumer-centred care and significant to effective treatment and management of health care issues (Birkhäuer et al 2017).

There were two distinct aspects of trust for the participants in this study that influenced their self-management experience in hospital. The first aspect was acknowledging the complete trust they had in their own ability to self-manage their T1DM both within and outside of hospital. The second aspect was the need to trust in health professionals to provide support for their T1D self-management both in and out of hospital. Further, there were variations in the level of trust participants had in the health professionals they knew out of hospital compared to those they interacted with in hospital. These two aspects of trust are similar to the dimensions of trust identified by Robinson (2016, p. 7); 'trust in one's own ability to manage illness' and 'trust in providers' of healthcare. The two distinct ways in which participants experienced trust issues in relation to their T1D self -management are discussed in 6.3.1 and 6.3.2 (see pages 101 & 102).

6.3.1 Trusting self

The participants distinctly trusted their own ability to self-manage their T1D both out of and in the hospital environment. The trust in their self-management abilities had developed through years of lived experience with their T1D which enabled them to draw upon their countless experiences to make multiple daily self-management decisions. As Lisa explained

> *I know myself, I know my body, I know how my insulin works so I felt very protective of myself...that only I can do it* (manage her T1D) *(Lisa FG).*

Having trust in their own self-management capability enabled the participants to rely on themselves to make the best decisions at any given time, based on the information they have such as BGLs or symptoms experienced.

Apart from themselves, some participants expressed their trust in a significant other to be able to support them to self-manage should they be unable to monitor their own BGLs. Trish trusted a close friend, who also had T1D, to manage her T1D on her behalf when she needed a break from her self-management. Trish stated:

> *I only trust myself. Well, no that's not true. I do…,*(trust) *my girlfriend, I quite often have holidays, so I go to her place and say 'you need to deal with this today so I can have a holiday'. I trust her to do it* (manage T1D) *(Trish FG).*

Other participants trusted a family member to be able to perform some self-management tasks on their behalf should they be unable to perform the task themselves due to feeling unwell. While Bianca knew she could perform blood glucose monitoring (BGM) herself, even when she was really unwell, she also knew she could rely on her Mum if needed.

> *I've been pretty sick but still been able to do my own testing and that….Otherwise….my mum would…. test me if I needed (Bianca Int. 10).*

However, Bianca was aware that no one she trusted knew how to manage her pump so she could only trust herself to manage it. She said:

> *…. no one really knows how to use my pump. So, it's up to me really* (to manage the pump) *(Bianca Int. 10).*

While the participants trusted in their own ability to manage their T1D Susan recalled making the decision to only trust herself based on the advice she received over 30 years ago;

> *Oh many, many years ago a nurse told me never let a doctor or the staff manage the diabetes and that was 30 years ago almost so I have always said I will do that myself (Susan FG).*

Susan continued to follow this advice ever since she received it all those years ago, which indicates the unwavering trust she has in her own ability to manage her T1D.

6.3.2 Trusting health professionals

Participants indicated they did trust their usual diabetes health professionals who they knew supported their T1D self-management. The trusting relationship the participants had with their usual diabetes health professionals had developed over a period of time outside the hospital. Some participants had long standing relationships with their diabetes specialist, which enabled them to develop rapport and trust with these health professionals leading to collaborative supported care. Predominately, these health professionals were identified by the participants as Endocrinologists and Diabetes Educators. Rasmussen, Wellard and Nankervis (2001) found people with T1D identified Endocrinologists as being central to providing the appropriate support people need to successfully self-manage their T1D. Similarly, the Type 1 Diabetes Network (2011) survey found that people with T1D identified the Endocrinologist and Diabetes Educator had the most understanding of T1D as a chronic condition and of the day to day challenges associated with living with T1D.

Robinson (2016) described the type of relationship, when there is high trust in both the health professional and in one's own ability to care for their chronic condition, as team playing. The team playing relationship is seen as collaborative and respect is shown for all members of the team so trust is built among the team players and its reciprocal (Robinson 2016). Furthermore, these types of relationships demonstrate affirmation to and validation of the person with T1D and their self-management capability by health professionals (Robinson 2016), thus strengthening the relationship.

However, some participants in the current study could not access their trusted diabetes health professionals during their recent hospital admissions because the health professionals did not have visiting rights to the hospital to which the participant was admitted. In addition, some participants were admitted to hospitals that did not employ a Diabetes Educator so the participants had no access to alternative support for their T1D while in hospital. As a result, some participants were left with no support from a health professional with any diabetes expertise during their hospitalisation.

6.3.3 Experiencing trust issues with health professionals

The reciprocal trusting relationships that developed with health professionals outside the hospital; usual diabetes health professionals, were non-existent for the participants when in hospital. In hospital, the participants with T1D believed they did not have the opportunity to develop rapport and a trusting relationship with health professionals. For example, some participants were only in hospital overnight or for 1 to 2 nights (see Table 4 on page 84), which can limit the development of a trusting relationship (Sahlsten et al 2005; Larsson et al 2007).

In addition, the participants' developed their mindset around trusting health professionals to provide appropriate care as a result of previous negative interactions and outcomes concerning T1D management in hospital. These negative interactions and outcomes could be linked back to the participants' perception about health professionals' limited T1D knowledge, which can inhibit the establishment of a trusting relationship with the health professionals, leaving the participants feeling insecure in hospital (Rasmussen, Wellard & Nankervis 2001; Harrison et al 2017). Within the current study two distinct trust issues emerged from the data. Brennan et al (2013) suggested a lack of trust in health professionals generated from previous experience can be defined as distrust. In addition, the participants in this study experienced a 'general sense of unease' about health professionals' capacity to manage their T1D, which Brennan et al (2013, p. 686) defined as mistrust. Participants in this study experienced both *mistrusting health professionals* and *distrusting health professionals* to provide appropriate care of their T1D in hospital.

6.3.4 Mistrusting health professionals

The participants indicated their general mistrust in health professionals in hospital was a result of the participants' belief that they could only trust themselves to manage their T1D correctly. This belief was reinforced due to their previous negative experiences in hospital concerning their T1D management. Omodei and McLennan (2000) suggested mistrust in health professionals indicated the participants did not trust the actions of the health professionals in relation to their own well-being in hospital. As a result of this mistrust, participants indicated the health professionals would not provide the same level of care for their T1D as they could for themselves.

As Trish stated:

> *I only trust myself. Trust self to manage T1D…..I don't have the faith in nursing staff to look after my diabetes (Trish FG).*
>
> *….I find it hard to then hand it* (T1D management) *over to someone else and trust someone else to do that* (manage T1D correctly) *(Trish Int. 5).*

Marie had a preconceived idea that the health professionals would not provide appropriate care for her T1D once she woke from her surgery. However, she was disappointed to discover she could not trust the health professionals to manage her T1D while she was under anaesthetic.

> *I'll take care of it* (T1D) *as soon as I'm awake because I knew that they* (health professionals) *wouldn't. I didn't trust them to do it but I thought they would at least get that small period of time during the surgery and before the surgery right. I was just wrong (Marie Int.12).*

As a result of this experience Marie developed additional mistrust for health professionals. Therefore, Marie felt satisfied when they left her to manage her T1D while in hospital. She said:

> *…. it was all left to me* (T1D management) *which was fine because I didn't trust them anyway (Marie Int.12).*

There was also a sense from the participants that they were *asking for trouble* if they did trust the health professionals with their T1D management (Susan FG). This mistrust stemmed from the realisation that health professionals do not have the experiential knowledge or expertise the person living with T1D has of their own body's response to BGL changes. Susan captured the risk of trusting the health professional as the quote below illustrates:

> *No one knows our bodies as well as we do, I think we know the numbers we should be putting in and what we should be eating and I think if you start to let somebody else try and manipulate that I think you are asking for trouble (Susan FG).*

Rasmussen, Wellard and Nankervis (2001) found when people with T1D had encounters with health professionals in the health care system who had a limited knowledge of T1D, it inhibited the establishment of a trusting relationship with those health professionals.

The overall general feeling of *mistrusting health professionals* to manage the participants' T1D also led to the participants questioning their entire episode of care while in hospital. They questioned the care they received for their primary admission diagnosis, which exacerbated their doubt about whether they could adequately trust the health professionals in relation to their T1D management in hospital. Marie stated:

> *I fear that the way they mismanaged my diabetes is a bit of a red flag as to how they manage other things as well (Marie Int. 12).*

Ravenscroft (2010) found that it may be difficult for patients to alter their expectations of health professionals and their perceptions of the hospital environment, which can lead to an overall lack of confidence in the entire system. The overall lack of confidence can impede the development of trust with health professionals in hospital. Berry et al (2017) stated that if the patients are not able to trust the health professionals the confidence in the relationship is diminished.

Trust has previously been identified as a significant factor in influencing patients' acceptance of and satisfaction with health professionals' recommendations along with their adherence to such recommendations (Brennan et al 2013). The current study found that the lack of trust the participants had in health professionals meant that the participants were reluctant to accept the health professionals recommendations about their T1D management in hospital. 'Non acceptance' or rejection of health professionals' recommendations was especially evident if the recommendations conflicted with the participants' predictions of what the outcome of accepting the health professional's advice could be. Furthermore, they chose not to adhere to recommendations the health professionals gave, because they knew from their own experiential knowledge that if they followed the health professional's advice, their T1D would not be appropriately managed. Trish trusted knowledge about her body's response to sitting around in the hospital being unwell would have on her BGL and predicted her requirement for additional insulin. When the health professional suggested she reduce her basal rate on her pump Trish did not accept the recommendation and did not adhere to the recommendation. Trish stated:

> *I wasn't going to change my basal rate or reduce it by 10% and I just went* (said to the health professional) *'got it'….and by 11 o'clock that night I was 26* (mmol/L). *You reckon I was turning my pump down by 10%? I am turning my pump up by about 50 dialling it up every 20 minutes. I sat it at 26* (mmol/L) *for 24 hours, it was so high. I could not get it* (BGL) *down (Trish FG).*

Trish's actions demonstrated a high trust in her own competence and showed a low trust in the health professional's suggestion. Robinson (2016) described this type of relationship as consumerism where the patient is taking responsibility for their health care through decision-making and problem-solving while simultaneously convincing the health professional they would accept their recommendation when they had no intention of doing so. In the current study, some participants who chose not to follow the health professional's recommendation for T1D management did so to keep themselves safe from health professional recommendations they did not trust.

6.3.5 Distrusting health professionals

Weber and Carter (2003, p. 80) suggested that when we place our trust in others we 'inherently believe we are not at risk'. The participants in the study recognised through their previous hospital experiences, that they were at risk if they placed their trust in the health professionals to manage their T1D; distrust (see definition on page 104). James explained his distrust in the health professionals to manage his T1D in hospital during his most recent admission was due to prior experiences. He believed his BGLs were erratic because his T1D was managed by health professionals .James said:

> *….they totally mess you* (T1D management) *up…. You just can't get through to them…I said, 'I should have a little bit of insulin before I go down there* (have a procedure) *'cause by the time I get back at lunchtime I will be too high'. 'No you're not allowed to have anything' so when I come back I was 18* (mmol/L) *but you know they treat you as a total idiot and that you know nothing (James FG).*

James had previously been admitted for the same procedure and had experienced health professionals not listening to his concerns about his BGL management and insulin administration. As a result of being *messed up* (described by James in the FG), he was dissatisfied with the health care he received and the recommendations health professionals made about his T1D management, which led to his mistrust of health professionals during subsequent hospital admissions (Brennan et al 2013).

Williams' (2004) suggested previous experiences in hospital led patients to pre judge health professionals' level of capability in the subsequent care they would provide during future episodes of hospitalisation. Williams (2004) specifically found those with underlying comorbidities admitted to hospital for an acute episode of care experienced a lack of trust in nursing staff's ability to provide competent care for their comorbidities. Williams (2004) finding aligns with the experiences of participants in the current study with the consequence of previous interactions in hospital with health professionals leading to a lack of trust of health professionals to safely manage the participant's T1D in hospital.

The current study also found some participants felt so distressed by health professionals' attitudes towards their T1D self-management that trusting them to provide appropriate care during the next admission was greatly impacted upon. Trish felt so distressed from the treatment she received during a recent admission that despite the need to be readmitted to hospital she was refusing. Trish explained:

> *… I'd been admitted two weeks or three weeks beforehand in such poor, with such a poor outcome again about self-management that I just flatly refused to go in* (to hospital) *by ambulance, which is really quite unfair (Trish Int. 5).*

Trish felt that it was unfair on her to feel so concerned about being admitted to hospital even though she was acutely unwell and needed tertiary treatment of her primary admission diagnosis. Trish was eventually taken to hospital by private car only after her partner consulted her usual Endocrinologist who determined Trish's safety was at risk if she stayed at home.

Overall the participants indicated they did not trust health professionals to be able to provide adequate care for their T1D. According to Brennan et al (2013, p. 682) the concept of trust has been linked to 'relations of dependency between experts and non-experts'. In relation to the expert and non-expert dependency in trust, it is usual for the patient to trust a health professional because they are seen as the expert, while the patient is deemed the non-expert (Brennan et al 2013). However, the participants in the current study self-identified as the expert in their T1D self-management. Furthermore, it was clear to the participants in a number of their hospital experiences that the health professionals were the non-expert on T1D management. Therefore, the role of the patient and health professional in the context of trust was reversed and as a result led to the participants with T1D *experiencing trust issues* with the non-expert health professional.

Participants in the study anticipated issues of trust would continue with health professionals in future episodes of hospitalisation. Brennan et al (2013, p. 682) acknowledged trust can be linked to ‘expectations about future behaviours/interactions’. This sense of mistrust for future care exists as they do not feel the health professional is trustworthy to provide them with appropriate management of their T1D. Jane expressed concern about a future episode of hospitalisation where she felt she may not be able to manage her own T1D due to effects of surgery and was worried the health professionals would not be able to manage her T1D due to previous experiences in hospital leading to limited trust in the health professionals. Jane said:

> *I have to have surgery soon and I must admit that is worrying me ‘cause I have never had surgery since I have had diabetes. That* (admission for surgery) *is worrying me (Jane FG).*

Similarly Eve worried about future episodes of hospitalisation especially if she was unable to manage her T1D herself. Eve explained that her worry about future hospitalisations stemmed from the general mistrust she has in health professionals being capable of managing her T1D her way. Eve stated:

> *I do worry about stuff like if something happened where I wasn't well enough or conscious enough to manage it* (T1D)….*I just don't think that they* (health professionals) *would be able to manage it the way I would (Eve Int. 9).*

Overall trust is important for communication and collaboration between patients and health professionals in hospital and a requirement for the practice of patient-centred care (Jones 2015). Participants in this study did experience limited communication and collaboration about the care of their diabetes. The participants were often left to self-manage without any discussion about what their self-management entailed and there was minimal collaboration around T1D self-management at multiple points during the hospital admission. This issue is discussed in *Experiencing limited diabetes discussions* (see 6.5 on page 121). However, Trish was happy to acknowledge the trust issue existed and wanted to improve on her lack of trust in the health professionals through open communication. Trish stated:

> *I'm happy to say, look, I find it really hard to trust you, but I'm prepared to work at this and open those channels of communication (Trish Int. 5).*

Brennan et al (2013) acknowledged that, while patients are in a more vulnerable position in the patient/health professional trust relationship, reciprocal trust, is required for an effective patient/health care professional relationship and important for patients experiencing positive healthcare outcomes. Furthermore, Robinson (2016) suggested for effective relationships trust is more than just a one way street and requires both patients and health professionals to demonstrate behaviours which allow for both parties to trust one another.

The flipside of participants not trusting health professionals in hospital is the recognition by the participants that health professionals do not trust their capacity to self-manage. An example of not feeling trusted by health professionals to self-manage was experienced by Susan when she was receiving treatment in a hyperbaric chamber. Prior to entering the hyperbaric chamber the policy of the health facility was that people with diabetes were required to have a BGL above a specific target. Initially the health professional monitored Susan's BGL prior to entering the chamber despite Susan displaying her most recent BGL on her BGM. However, over the period of a week Susan was able to undertake her own BGM.

> *….I said 'oh look I've already done it'* (BGL) *but then by about the end of the first week I think they realised I could do it myself and they would just say 'oh what was it?' And that was fine so they handballed it to me when they knew that I could do it (Susan FG).*

A participant in the Type 1 Diabetes Network (T1DN) survey stated the one message they wanted health professionals to understand about living with T1D was 'I have been a diabetic for 30 years, trust me, I know a bit about it!' (T1DN 2011, p. 27). People with T1D are known to develop expert knowledge about their own condition, which health professionals are known to be reluctant to trust (Thorne, Ternulf Nyhlin & Paterson 2000). Wilson, Kendall and Brooks (2006) found that physical measurements, such as HbA1c, were heavily relied on by nurses to determine whether they could trust the patient's level of diabetes self-management expertise. Nurses' reliance on physical measurements, and not the patients' expertise, created a complex interactional dynamic that detracted from mutual trust and effective relationships being built with people with T1D (Wilson, Kendall & Brooks 2006).

Entwistle and Quick (2006) recognised the concept of health professionals' level of trust in their patients. They suggest the level of trust health professionals have in their patients may affect the patient's experience of being in a health service and may impact on the patient's trust in health professionals considering the development of a trusting relationship needs to be reciprocal (Entwistle & Quick 2006). The participants in this study believed the health professionals should have trust in their T1D self-manage capability in hospital. However, due to the limited diabetes discussions that occurred within the hospital for the participants with T1D, it would seem difficult for the health professionals to assess the participant's self-management capacity and subsequently establish trust in the participant's capabilities.

Ultimately, patients' level of trust in health professionals in hospital influences their feeling of being safe from harm while they are an inpatient (Entwistle & Quick 2006). For participants in the current study the trust issues they had constructed with health professionals in hospital influenced their need to keep themselves safe during their most recent hospital admission in relation to their T1D management.

6.4 Feeling judged

According to Rauch (2016) the word judge has an overall negative connotation and potentially situates people in no win interactions. As a result of this negative connotation people do not like to be judged especially as such judgement may cause shame when one's beliefs, preferences, decisions, character or intelligence are questioned by others (Rauch 2016). However, there are a range of ways people judge situations and other people and these judgements can be interpreted as either negative, positive or neutral (Rauch 2016). Participants with T1D in the study interpreted their interactions with health professionals in hospital. Their interpretation led the participants to construct their understanding of how they were being judged in relation to their T1D self-management. Predominately *feeling judged* was a result of the interaction with the health professionals around the participants' capacity to self-manage their chronic condition in hospital. There were two sub categories within the main category of *feeling judged*; 1. *feeling judged as* *incapable* to self-manage their T1D and 2. *feeling judged as capable* of self-managing their T1D in hospital.

6.4.1 *Feeling judged as incapable*

The first sub-category, *feeling judged* as being incapable to self-managing their T1D in hospital led the participants to feel that the health professionals viewed them as unable to self-manage. This kind of judgement was interpreted negatively by the participants and further hindered the fostering of trust and feeling of competence in the health professionals. Furthermore, negative judgement was seen as a threat to the person's identity because it challenged their preferences, decisions and intelligence around their usual self-management. Lucy felt judged by health professionals as being incapable of self-management following a surgical procedure. The judgement occurred despite Lucy feeling very capable of continuing her T1D self-management. Lucy explained:

> *I feel very capable of doing it* (self-management) *but, unfortunately, most of the staff on the surgical wards don't think you are capable of doing it, even when you've come out [of] the anaesthetic (Lucy Int. 1).*

Lucy had arranged pre-operatively with the Anaesthetist to continue to self-manage her own pump after she woke from her anaesthetic. However, Lucy found she needed *to fight the* (nursing) *staff to let me do it* (manage her pump) (Lucy Int. 1). Lucy viewed these judgements as baseless because none of the surgical ward nurses had initiated any conversation with Lucy about her ability to manage her pump post-operatively. Consequently, Lucy viewed *feeling judged* by the health professionals in an even more negative light because she was not provided with any evidence or justification for why they thought she was not capable of using her pump.

As well as feeling judged, Lucy also experienced the staff being *very impolite* to her about her resuming self-management of her T1D (Lucy Int. 1). An example of an impolite health professional interaction for Lucy was with a Doctor who *lectured* her about her diabetes management. Lucy stated the Doctor said to her;

> *….that I should be letting them do it* (manage her T1D). *That they knew best which was very obvious they didn't (Lucy Int. 1).*

Similarly, Trish felt she was being judged as incapable of self-management of her T1D in hospital. Trish interpreted her interactions with health professionals in hospital as being dismissive of her many years of lived experience with self-managing her T1D because she was given no credit by health professionals for her ability to manage. She said:

> *….as a person with type 1, having managed my chronic disease for 32, 33 odd years, I'm given no credit whatsoever for my ability to manage my condition by most of the health professionals (Trish Int. 5).*

Trish also felt her voice, as a person who has had considerable self-management experience, was diminished by the judgement directed towards her by the health professionals.

> *When you get admitted to a hospital setting, you lose your voice completely (Trish Int. 5).*

Another aspect of *feeling judged* as incapable was when participants *experienced blame* from the health professional when their blood glucose levels were outside acceptable hospital parameters. In a general ward environment in hospital it is recommended that BGL should be maintained between 5 – 10mmol/L to prevent hypoglycaemia and hyperglycaemia (Australian Diabetes Society (ADS) 2012a). Marie experienced a health professional directing blame towards her for an elevated BGL. She had just undergone a five hour surgical procedure under general anaesthetic so her T1D was being managed by health professionals. After waking from the anaesthetic Marie immediately knew her BGL was elevated based on her symptom of being thirsty. Marie said:

> *But I knew when I woke up I was so thirsty. I knew that they hadn't looked after me properly and then I had the nurse come in…..one of the nurses came up to me and said, 'oh your blood sugar went up to 17' like it was my fault. I just went 'oh'. That really bothered me that they could be so ignorant (Marie Int. 12).*

The interaction with the nurse bothered Marie because she had entrusted the care of her diabetes to the health professionals while she was undergoing a surgical procedure and believed it was their role to maintain her BGL within an acceptable target range while she was under general anaesthetic. Marie felt the nurse was being ignorant in directing blame towards her when her BGL was outside of her control and the management of her BGL was with the health professional while she was under anaesthetic.

Similarly, Trish felt judged by health professionals about her elevated BGLs, which Trish linked directly to the health professionals' *complete misunderstanding of the disease state* and what it entails to manage the condition (Trish Int. 5). An Endocrine consultant visited Trish while she was in isolation for an admission diagnosis of Influenza B and blamed her for her elevated BGLs.

> *….*(Endocrine consultant) *proceeded to continue to give me a hard time about the fact that I was running blood glucose levels between 11 and 13* (mmol/L)*, and 11 and 15* (mmol/L)*, after each meal, which consisted of things like white bread sandwiches, and no ability to have any control over my meals….he decided to tell me that once I was no longer contagious for influenza B, that if he released me, that he could quote, unquote, almost 100 per cent guarantee that I would be back in DKA within 24 hours….because I clearly wasn't managing my diabetes effectively (Trish Int. 5).*

When Trish tried to explain to the Endocrine consultant that while in hospital she had her self-management tools 'taken away' from her she received further judgement about what type of diet she may follow out of the hospital without the Endocrine consultant discussing Trish's usual self-management with her. Trish explained:

> *'Someone that's diagnosed with diabetes get some tools', and he goes, 'I'm sorry, I don't understand your question'. I said, 'do we not take into consideration that people with diabetes get blood glucose monitoring, physical activity, healthy food choices and some form of medication, of which I have to have insulin'. He goes, 'well yes'. I said, 'so you've taken two of my tools away…..You've taken physical activity, which, I understand, because I'm not well at the moment, and healthy food choices' and he rolled his eyes at me….because I said, 'you can't get a decent meal in the public system if your life depends on it'. He rolled his eyes at me and said, 'you're one of these people that eats low carb, high protein meals' (Trish Int. 5).*

People with T1D are often held responsible by health professionals for maintaining target BGLs and can fear negative feedback from health professionals if they do not maintain optimal BGLs (Schabert et al 2013). However, there are numerous factors that are out of the control of the person with T1D when they are in hospital and these factors can affect their BGLs, including infection, stress and medications such as glucocorticoid steroids. Two participants in the study received glucocorticoid steroids and predicted the medication would increase their BGL. As a result, they altered their insulin doses in order to counterbalance the resulting rise in BGL. As Trish had previously experienced the effects of a corticosteroid injection she informed health professionals of her experience from a previous hospital admission when her BGL increased to 29mmol/L. Trish said:

> *They had notes to refer back to, and I'd said to them, the last time I was here, I hit a blood glucose level of 29 or something, and they actually referred back to that (Trish Int. 7).*

However, the health professional only listened to the predication Trish made after they read the documentation in the case notes to validate what she was saying was correct.

> *They went, 'ah, you're right', so I wasn't, I wasn't just someone that was saying it without some form of documented evidence (Trish Int. 7).*

Participants also experienced *feeling judged* when their BGL went below an acceptable target range (hypoglycaemia). Trish, who was confined to bed following a procedure, recognised she was experiencing symptoms of hypoglycaemia when she began to *shake and sweat* (Trish FG). However, Trish's interpretations of her body cues were judged by the health professional as *ridiculous* because the health professionals had performed a BGL 30 minutes earlier that was within an acceptable target range (Trish FG). Furthermore, health professionals had moved from Trish's reach one of the tools she used to self-manage her T1D, which this left her reliant on the health professional to monitor her BGL.

> *….so they had left the room and I was here and my blood glucose monitor was left on a bench over there and I thought 'I reckon I'm hypoing' and I'm not close enough to get anywhere near a meter* (blood glucose meter), *buzzed the bell, nothing, buzzed the bell, nothing by this time I am starting to shake and sweat, buzzed the bell, still nothing, the only thing I could get close to was my mobile phone and so flicked my mobile phone over, rang my girlfriend who's a nurse and I went 'what do you have to do to get staff in here quickly?' and she said hit the bell 3 times, so then they all came running and I said 'I reckon I'm hypoing', to which I had a nursing staff say 'don't be so ridiculous, we only did a BGL only half an hour ago and you were 8' and I went 'can I please have that over there* (blood glucose monitor)*?' and she did it* (BGL) *and I was 2.1, so then she left and came back with a glass of water and 3 teaspoons of sugar, and I went 'I am so not drinking that. I want my bag of lollies' (Trish FG).*

Trish's recollection of the interaction with the nurse was her concern of experiencing hypoglycaemia was dismissed Trish recalls the nurse was dismissive of her hypoglycaemia symptoms by stating her BGL had been 8mmol/L 30 minutes prior to Trish pressing the bell.

Thorne, Ternulf Nyhlin and Paterson (2000) acknowledged health professionals tend to focus on rationalising responses to illness through biomedical science such as in the case when symptoms of hypoglycaemia do not match a recent BGL result.

The literature reviewed in Chapter two did suggest patients' self-management expertise is judged against physical measurements. Furthermore, the reliance on trusting patients based on objective data influences the health professionals' judgement on the person's ability to self-manage their T1D in hospital (Thorne, Ternulf Nyhlin & Paterson 2000; Paterson 2001; Wilson, Kendall & Brooks 2006). While this literature is over 12 years old, it is important to acknowledge that the same judgements towards people self-managing their chronic condition remain relevant to the experience of the participants in hospital in the current study. A recent study by Griscti et al (2016, p. 242) with a cohort of patients with chronic conditions in hospital found that the 'patient's knowledge about their body was not always respected'. In their view the lack of respect for the patients' knowledge occurred due to the institutional medical discourse, which privileges the health professionals' expert knowledge over the lay knowledge of the patient with a chronic condition (Griscti et al 2016). Potentially, health professionals make judgements about people with chronic conditions as a consequence of the dominance of the medical model, which privileges acute illness over chronic conditions (Griscti et al 2016a).

Feeling judged in a negative way and feeling blamed by health professionals about T1D self-management in hospital is a contributing factor to health related stigma (Schabert et al 2013). In general stigma is a social process 'experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group' (Weiss, Ramakrishna & Somma 2006, p. 280). Furthermore, such judgement is based on an aspect of identity 'conferred by a health problem or health related condition' and this type of judgement is seen as medically unwarranted in relation to the actual health issue (Weiss, Ramakrishna & Somma 2006, p. 280). For example, Dave stated that he felt the health professionals in hospital viewed him as a bad person based on how he manages his health problem.

> *They're going to think I'm a bad diabetic. They're going to think I'm a bad person (Dave Int. 11).*

Link and Phelan (2001) identified stigma is usually related to power differences between those with the condition that is stigmatised and those without the stigmatised condition. Participants in the current study could be viewed as the stigmatised group as opposed to the health professionals without the stigmatised condition being seen to have more power. However, the participants were already influenced by the socially constructed power differential between the health professional and patient despite the stigma power differential.

In recent times the concept of stigma, related specifically to diabetes, has become recognised in the literature (Schabert et al 2013). Diabetes-related stigma can be linked to feeling blamed and fearful, which were two areas identified by participants in the current study. As a result of experiencing health related stigma, people may be less likely to access or engage in healthcare (Browne et al 2017). Trish experienced barriers towards engaging with health professionals when she felt judged by a Doctor during her hospitalisation with a primary diagnosis of Influenza B.

> *….to be automatically judged and automatically, well you're obviously in here because you can't manage, otherwise you'd be home, I find that then just…. puts up more barriers* (between the health professional and patient relationship) *(Trish Int. 5).*

Schabert et al (2013) found people living with diabetes report feeling judged and constantly monitored, thus they experience a socially constructed stigma around their diabetes. Participants in the study found the judgement of their capacity to manage their diabetes existed in the hospital and judgement was directed towards them by health professionals within the hospital. Ironically, health professionals who judged participants demonstrated through their interactions that their understanding of T1D management was limited. Furthermore, their interactions around diabetes management were minimal, and in some cases, the secondary diagnosis of TID was completely ignored. The *identifying limited knowledge of health professionals* and *experiencing limited diabetes discussions* are discussed further in 6.2 and 6.5 (see page 89 & 121).

The reduction of seeking help and engaging with health care due to stigma can result in an increased risk of developing health complications associated with diabetes. However, the participants in the study who experienced health related stigma in hospital, through health professionals' attitude of blame (Schabert et al 2013), became more determined to manage their T1D themselves as they felt the judgements they were subjected to were unwarranted and misinformed. Dave stated:

> *….until medical staff in general recognise the fact that people can actually manage this disease quite well thank you very much and only when they get in real trouble do they want to call on you to take over, there is a bit of judgement there. There's always a bit of judgement (Dave Int. 11).*

As Schabert et al (2013) discussed, fear of judgement or negative appraisal in relation to diabetes self-management can lead to reluctance to share information with health professionals. Reluctance to share information can lead to people with diabetes to conceal what equipment they brought into hospital with them to self-manage or the kinds of foods they have in their possession to manage hypoglycaemia should it occur in hospital. While Schabert et al (2013) suggested concealment of aspects of diabetes management due to fear of negative appraisal can compromise self-management, the current study found that participants may have concealed aspects of their self-management in hospital to keep themselves safe from harm. For example James learnt from previous hospital admissions that he would have his insulin pens removed because the nurses were adamant that all insulin was to be stored in the refrigerator. In order to keep his insulin with him James concealed his insulin pens from the nurses.

> *They* (the nurses) *don't get them* (insulin pens) *cause I don't tell 'em (inaudible laughter in room). I don't even tell 'em I've got it until its injection time. 'I've got my own* (insulin) *in the drawer', 'well it should be in the fridge', 'no, no don't worry about the fridge' (James FG).*

Similarly, Lucy concealed diabetes self-management equipment from health professionals to protect herself from potential harm after hearing about other people's experiences with their *hypo stash* in hospital (Lucy Int. 1).

> *It* (diabetes self-management equipment) *stayed with me. I didn't tell them it was there….Because I have read enough from other people, or heard enough from other people, about their hypo stash being taken, about them being told, no they couldn't have that with them. I thought I'm not going to even tell you (Lucy Int.1).*

Schabert et al (2013) developed a framework for understanding diabetes-related stigma (see Appendix 17 on page 280). Some components of the framework were relevant to the experiences of the participants in the study and their self-management experiences in hospital. The components within the framework that were relevant in the study are *perceived stigma* such as being judged, *stereotypes* such as being identified as lacking control if BGLs were elevated and some *stigmatizing practices* such as being treated differently by health professionals in hospital as a direct result of having T1D (compared to people who don't have T1D) (Schabert et al 2013). All of these experiences can threaten one's identity (Schabert et al 2013) and for the participants of the current study threats manifested in the form of being labelled as non-compliant or being judged as not being able to effectively self-manage their T1D. As a consequence of the experiences of stigma participants in the study experienced *fear* and *worry* for their safety in hospital and did attempt to conceal some aspects of their self-management as a behavioural consequence of stigma from health professionals.

6.4.2 *Feeling judged as capable*

Not all participants experienced negative judgements by health professionals. Some participants felt they were judged in a positive way by health professionals as being capable of self-managing their T1D in hospital. However, there was no assessment of the participants capability performed by the health professionals. Instead participants were judged as capable based solely on them stating they could manage their T1D in hospital, or health professionals simply believing the participant could manage on their own. Bianca said:

> *I think they* (nurses) *gauge that you've got it* (diabetes) *under control so they just leave it to you (Bianca Int. 10).*

When questioned further, Bianca explained that in a previous hospitalisation she experienced nurses asking her a few questions about her pump or BGL. However, Bianca's overall impression was that nurses didn't enquire about the pump because they didn't necessarily want to know about it or it was one less thing for them to manage on their shift.

While Eve felt she was judged as capable of managing her pump, she believed health professionals didn’t understand the effort required to manage the pump. Eve thought there was an overall misconception amongst health professionals that the pump was an easy aspect of self-management of T1D.

> *Everyone sort of says, oh so she's on an insulin pump so she's all fine - it's all easy to manage and everything else. It's like, ah, sort of no. It's like an every moment of the day for the rest of your life type thing (Eve Int. 9).*

A downside to *feeling judged* as capable to self-manage in hospital was to then be left unsupported with all aspects of diabetes management. Lisa informed her surgeon that she wanted to self-manage her T1D post-operatively. However, this meant that Lisa was solely responsible for monitoring her BGL every hour overnight, which left her feeling exhausted.

> *I just found being in hospital I was exhausted. Having to keep waking myself up every hour to do a test. You know you would reach over and go it’s there, it’s there, right get it, do a test and go, oh what is the number?, oh ok it’s that and then have to attend to it yourself all the time for me was exhausting especially its night time, I’m normally asleep, I don’t normally have to wake myself up every hour to do this....(Lisa FG).*

So while Lisa felt capable of self-managing and the health professional agreed with this, Lisa stated:

> *….it would have been nice to have someone stand by just to ensure you were doing it* (BGM) *and that you were reading the numbers* (BGL) *ok…. even just to say ‘wake up Lisa and do a test now’ would have been nice (Lisa FG).*

Similarly, Trish explained that as soon as she told the health professionals she would self-manage, health professionals showed no interest in her diabetes management. Trish said:

> *….I’m actually ok to do it* (self-manage T1D)…. *they* (health professionals) *completely wipe their hands of any diabetes management what so ever…. There is the expectation you will look after yourself (Trish FG).*

Overall *feeling judged* as capable of self-managing T1D in hospital by the health professionals was seen as a positive judgement on the participants’ capability. However, the judgement was unsubstantiated and may have been based on a misunderstanding of the complexity of T1D self-management. Moreover, the consequence of positive judgment often left participants feeling unsupported in hospital. The judgements made by the health professionals reinforced to the participants that health professionals have a limited understanding of T1D and the complexities of self-management of T1D, which also reinforced the need for participants to keep themselves safe in the hospital.

6.5 Experiencing limited diabetes discussions

According to the Cambridge Dictionary (2018) discussions are ‘the activity in which people talk about something and tell each other their ideas’. This definition suggests a discussion is a two way conversation in which ideas are shared and information is exchanged. Patients in hospital should have the opportunity to have a discussion with a health professional about the care they will be, or are, receiving (Australian Commission on Safety and Quality in Health Care (ACSQHC) 2016a). The ACSQHC’s consumer information on communication with health professionals in hospital states:

> ‘You can expect healthcare providers to communicate with you about your care, and for that communication to be two-way, clear, open, honest and offered in a way you can understand’ (ACSQHC 2016a, p. 4).

In addition, to being able to expect discussions around care in hospital, communication itself is seen as an important component of patient safety and quality care within the healthcare literature. According to the ACSQHC, patient-clinician communication is a significant component of ensuring quality and safety in health care (Iedema & Manidis 2013). The ACSQHC consumer information document also suggests ‘effective communication with’ the ‘healthcare provider is essential’ to ensure safe, high quality patient-centred care (2016a, p. 1).

The opportunity to exchange ideas between health professionals and patients supports the ideals of patient participation in health care and a consumer-centred care focus. Castro et al (2016, p. 1924) suggested that these ideals of patient participation and consumer-centred care have been ‘buzz concepts for quite some time now’. These ideals indicate that patients are no longer just passive recipients of care but rather, play an active role in making informed decisions about their own health care (WHO 2013; Sahlstrom et al 2018). In essence, patient-centeredness is an approach to care that meets the patient's 'needs, values and beliefs' through understanding the patient's 'expectations, perceptions and experiences' of their care (Castro et al 2016, p. 1929). In addition, patients being actively involved in their health care reduces the gap between the experiential knowledge of the person and the health professionals' knowledge (Castro et al 2016), which was found to be an issue in 6.2 and 6.3 (see pages 89 & 100).

Participants in the study expected to be included in discussions around their T1D management while in hospital. However, the opportunity for discussions with health professionals was limited throughout multiple points of their hospitalisation. While the study did not focus on the communication related to the participants' primary admission diagnosis, which may have been done well, there was certainly limited communication around T1D management in both the pre-admission appointment, the episode of hospital care and the discharge planning discussion. Due to the limited discussions initiated by health professionals, the participants initiated discussions with health professionals about how their T1D would be managed in hospital. However, some participants felt judged, dismissed and even ignored by health professionals when they initiated such discussion (see 6.4 on page 111). While person-centred care is recommended to assist in the safety of patients in hospital, when it came to T1D management in hospital, person-centred care seemed to be absent along with the safety focus. As a result of the limited discussions around T1D, participants came to the conclusion that their T1D was not important to the health professionals. They also concluded that the health professional does not value the knowledge the person with T1D holds about their condition; their T1D expertise.

6.5.1 Pre-admission discussions

Prior to a planned admission to hospital a number of the participants in the study had the opportunity to be involved in a pre-admission appointment. Marie had interactions with both the surgeon and the anaesthetist prior to her hospital admission. During this planned interaction Marie initiated a discussion with the surgeon about how her T1D would be managed while she was under general anaesthetic for cardiac surgery.

> *…. I asked the surgeon 'how are you going to manage things* (her T1D)*?' and he said, 'we'll do a blood test every 17 minutes to check you're okay'. That was all I got and apart from the anaesthetist telling me to half the dose of basal, which…. I think is incorrect, it* (T1D management) *was all left to me (Marie Int. 12).*

Therefore, even though Marie had a pre-admission appointment, she had to initiate the discussion about how her T1D would be managed in hospital and despite doing so, she felt the discussion was limited, particularly in relation to how the medical team would manage her T1D while she was under anaesthetic. In addition, she felt she was provided with incorrect information about pre-operative management of her T1D by the anaesthetist and was ultimately given the impression that the management of her T1D was her responsibility while she was an inpatient.

Kate had discussions with a number of health professionals specific to her T1D management in hospital prior to her admission. While Kate's endocrinologist and diabetes educator did not have visiting rights to the hospital where Kate's surgery was planned, they both consulted with another endocrinologist who would be available to Kate during her admission.

> *….my endocrinologist got me a fill-in endocrinologist and my educator actually messaged her and filled her in on my details. I had another anaesthetist which was new to the scene, and he rang me quite a few times and researched the pump and was comfortable with it. So yeah, we all worked together (Kate Int. 3).*

Kate therefore felt she had adequate discussions with the health professionals about how her T1D would be managed during her hospitalisation. As a result of the discussion, preparation and support, Kate felt satisfied with the pre-admission plan of care. However, while Kate felt she worked with the health professionals to decide how her T1D would be managed in hospital she said she did not feel comfortable with some aspects of the initial pre-admission plan.

> *Yeah, but the hospital, and even my own endocrinologist said, for a few days we want to take you off your pump and we want to have you on a drip. We want to do this and that, and I wasn't comfortable with that happening. In the end yes, I did it* (manage own pump) *and everything worked out fine (Kate Int. 3).*

Flanagan et al (2018) suggested that people with diabetes should be involved in planning their diabetes management in hospital for any elective admission. Such planning includes the pre-admission stage all the way through to the discharge of the patient. According to Flanagan et al

(2018), health professionals need to seek information at the beginning of their interaction with a person with T1D to determine whether the person with diabetes wishes to self-manage during their admission. The initial interaction represents an opportunity to ensure appropriate support can be implemented for the entire admission. Participants in the study who had planned admissions experienced minimal discussion about how their diabetes would be managed in hospital, let alone a discussion about self-management choices for the person with T1D. Lucy expected to be seen by a health professional in hospital pre-operatively because of her additional diagnosis of T1D however, this was not her experience. Lucy said:

> *I really thought that because of the type 1, that I should have been asked to go in to have all the tests and everything done at the hospital and have the preadmission stuff done in person (Lucy Int.1).*

Lucy’s experience was common amongst the participants who had planned admissions in the study.

6.5.2 Episode of care discussions

The majority of the participants experienced limited discussions with health professionals about their diabetes management needs during their episode of care. Clare had no specific recollection of a discussion about her T1D management during her admission to hospital. She said:

> *Not that I remember. Not apart from telling them* (health professionals) *what I was doing and how I was doing it and that I was doing it (Clare Int. 2).*

Clare indicated that her mentioning being on a pump to health professionals during her admission probably led them to assume Clare would self-manage. Consequently, her T1D management was not mentioned again during her episode of care.

> *When I got admitted there must have been a load of questions they asked and I'm guessing then it would have come up about the diabetes and I guess, well I would have told them that I was on the pump. So that probably covered it and then they knew that I was doing it and they didn't have to do anything so it* (diabetes management) *didn't come up again (Clare Int. 2).*

Eve similarly experienced having a discussion with health professionals where they asked her if she was fine to manage her T1D and when she indicated that she was they left her to manage on her own, this being Eve's preference. Following on from the original discussion Eve did not have any further discussion with health professionals about her T1D management in hospital.

> *….I think they just sort of say, 'oh and are you okay to look after that?' ….I obviously say, 'yes'. Yeah, I find that generally they ask me, they're like, 'oh are you fine to deal with that yourself?' They sort of leave me to it a bit…..I'm happier to look after it (Eve Int. 9).*

Trish acknowledged she has never been asked by the health professionals about her BGM. Consequently Trish continued to self-monitor her BGL because there was no discussion to determine otherwise. Trish stated:

> *No-one's ever said to me, 'do you want to do your own finger pricks, do you want to manage your own diabetes while you're here, or would you like a break?' (Trish Int. 5)*

As a result of these limited discussions the health professionals were not asking the participants about how they would prefer their T1D to be managed in hospital. Furthermore, health professionals made some assumptions that the participant with T1D would just manage their diabetes without any formal arrangements being discussed. Laura experienced not being asked about how she managed her diabetes while in hospital so she took responsibility for herself and monitored her own BGLs and administered her own insulin in recovery. Laura said:

> *So I had been for the day surgery, the two times before, they had barely asked me what I did…. I did my own blood sugars, just took insulin in recovery. They just said, 'are you right? Do you need anything?' 'No, nothing' (Laura Int. 6).*

Laura acknowledged that the health professionals did enquire as to whether she was *right* or if she needed *anything*. However, Laura had not experienced any formal discussion prior to her day surgery that she would self-manage her T1D after her procedure so there was no communication or establishment of any plan of care for her T1D. It would seem the health professionals were not documenting Laura's BGLs or the dose of insulin Laura was administering because Laura was not sharing that information with the health professionals as they did not ask her. Similarly Trish experienced no discussion around her insulin management in hospital. However, the health professionals did enquire about her BGLs and she recalled they documented her levels.

> *I was in a vascular ward, so pretty much they left me alone to manage my own diabetes….They asked me about my blood glucose levels and just noted them down. There was no interaction about what insulin I was using or how much insulin I was taking, if I needed insulin or anything like that (Trish Int. 8).*

Overall most of the participants in the study were not invited by health professionals to engage in discussions about their T1D self-management in hospital. Tobiano et al (2016) suggested that engaging patients in their care is a critical strategy for enhancing patient participation. However, the participants in the study all entered the hospital being actively engaged in their self-management and wanted to remain actively engaged. Yet, there was minimal encouragement by health professionals for participants to remain actively engaged because the discussions around T1D management were not occurring. One reason for the lack of discussion was explained in 6.2 (see page 89) where the participants acknowledged the health professionals did not have sufficient knowledge to understand T1D or T1D self-management so therefore did not engage in a discussion around T1D management. Eve hypothesised that health professionals may not know how to respond to her if she said she was unsure about self-managing her T1D in hospital. Eve said:

> *I guess if I said I wasn't sure or I didn't know how to manage, I don't really know what they'd do from that point. I think they might be a little bit dumbfounded and sort of go, 'oh, maybe you should see your health care professional or something'. I guess because I managed before they assume I'll manage after (Eve Int. 9).*

6.5.2.1 Specific incidences around hyper and hypoglycaemia

Laura initiated an interaction with a nurse overnight to request more insulin in response to detecting her BGL was elevated after a steroid injection, which is known to elevate BGLs. Laura was required to rely on nurses for support because health professionals had taken her insulin and syringes from her on admission to the ward. Therefore, she had no access to her own equipment and was unable to correct her own hyperglycaemia. Consequently, Laura needed to request insulin from the nurse to manage her hyperglycaemia. She said:

> *I think I asked three separate times* (for insulin)*, three, yeah, I think once in the evening and twice in the night and got the two units (Laura Int. 6)*

Due to Laura's inability to self-administer her insulin she was required to wait each time for the nurse to phone a doctor to request additional units of insulin. The fact the additional insulin required was not already available on the medication chart demonstrates the lack of consideration by the health professionals of the impact of administration of prednisolone has on BGLs. At one point Laura had to wait for over an hour before the nurse returned with the requested additional dose of insulin. Eventually Laura administered her own insulin from a pen she had accidently left in her handbag because she was *sick of asking* (Laura Int. 6).

> *I suppose I just got sick of the kind of attitude of we have control over your insulin and I just thought, oh look, it was about 7:00 - no, not even that when I had it* (insulin) *from my pen and just thought, oh look, I'm sick of asking. I'll just use this* (pen), *it's easier. But then in the night I suppose - why didn't I just do that? The second time I wished I had. It was sort of, oh I'll have to have some more insulin I said….It was sort of out of my mouth and then it was too late (Laura Int. 6).*

Laura questioned herself as to why she requested assistance from the nurse and did not just use her own pen in the first place. Laura was also told by a nurse to *try and get some sleep* because stress elevates blood glucose (Laura Int. 6). However, the nurse was not recognising the impact of the medication on Laura's BGL or the wait time for the administration of insulin, which meant Laura was not able to sleep.

The nurses did not acknowledge or initiate the need for additional insulin for Laura based on her elevated BGL. They did not take any action on their own accord and Laura recognised that without her raising the elevated BGL with nurses then no action would have been taken until the morning. Laura said:

> *….if I hadn't rung the bell or walked out or whatever, they would have just waited until the morning…. done my blood glucose and gone, 'oh look its* (BGL) *20* (mmol/L)*' (Laura Int. 6).*

Interactions such as this further reinforce that health professionals do not understand T1D or its management and interactions such as these, do not contribute to developing therapeutic relationships between health professionals and patients with T1D. The interactions between the patient and nurse, or health professional, are fundamental in their experience of receiving or delivering care (Stoddart 2012) with communication being essential for developing a therapeutic relationship. However, participants in the study experienced limited communication with the health professionals around diabetes management, damaging the therapeutic relationship, which then impacts on the trust that participants had in the health professionals to appropriately care for them as discussed in 6.3. According to Ringdal et al (2017), meaningful relationships between health professionals and patients are those that demonstrate respect for individual values, preferences and desires, which are essential for the development of therapeutic relationships.

Participants in the study attempted to report symptoms of hypoglycaemia or hyperglycaemia and on occasions were met with judgements, rather than support. Additionally, participants sometimes felt their preferences of care were being dismissed. Furthermore, they felt on occasions that their T1D management was being ignored by health professionals when they initiated discussion about their diabetes management needs. Marie requested information from the health professional about how much insulin she had been administered during her surgery. She received the following response from the health professional.

> *The morning after the surgery, I said, 'well, how much', when I was high* (elevated BGL), *'how much insulin did you give me?' and they said, 'oh, the basal dose'. I said, 'I think I need more' and they sort of just ignored me (Marie Int. 12).*

Similarly Jane felt ignored by health professionals in her attempts to seek help for her self-detected hypoglycaemia because she had no response when she pressed her bell multiple times. Jane's impression from the nurses was that receiving handover was more important to them than dealing with the fact her BGL was 2mmol/L and required immediate intervention to prevent her from experiencing a loss of consciousness. Jane stated:

> *…. I had a hypo the night I had the pump installed. It got down to 2* (mmol/L) *something…. Press the buzzer, nothing happened, press the buzzer, so I walked down to the thing* (nurses station) *and got told off for being out of bed with a hypo. I said 'what was I supposed to do you weren't coming?' 'Well it was change over* (handover time) *so how could we?' Well what I supposed to do? (Jane FG).*

Both participants were attempting to initiate discussions about their T1D management in hospital with the health professionals. Marie and Jane felt the interactions they experienced with the health professionals were inadequate and they were being dismissed for seeking information or support to manage their T1D. The patient experience in Australian hospitals review found reciprocal communication and information sharing was important to patients (Harrison et al 2017). However, participants in the study experienced a lack of reciprocal communication and information sharing, which led to negative constructions about their interactions with health professionals. As a result of not being listened to and when there is a lack of understanding of their perspective, patients report feeling distressed (Harrison et al 2017).

In addition, these limited responses from the health professionals around BGLs being out of target range suggest that the participants were unsafe in hospital and at risk of dire consequences. Out of target range BGLs are known to impact on length of hospital stay and increase the risk of infection developing in patients with diabetes (Dadlani et al 2017). In addition, Dadlani et al (2017) suggested that hypoglycaemia and hyperglycaemia in patients with T1D in hospital, increases workload of health professionals and increases cost to the health budget. The increase in workload comes from the required attention of nursing and medical staff to manage hypoglycaemia and hyperglycaemia along with the potential for additional laboratory testing for glucose results (Dadlani et al 2017). However, participants in the study were the ones managing, or initiating management, of their hypoglycaemia or hyperglycaemia without any support from the health professional as a result of limited discussions.

Castro et al (2016) explained that, for patients to be active participants in their healthcare, health professionals themselves need a positive attitude towards such participation. Furthermore, Castro et al (2016) stated health professionals need to value the expertise and knowledge of the patient as being equal and complementary to their own knowledge. However, the study participants felt health professionals were not necessarily expressing positive attitudes towards them and they were often dismissive of the participants' knowledge. In effect, the health professionals encountered by participants in the study were not practising in a manner that encouraged patient participation, which can be detrimental to the safety of the patient in hospital.

Eve experienced a lack of discussion by the health professionals who commenced her on a glucose drip without any consultation. Eve said:

> *They put me on a drip and then a couple of hours later after still eating no food or anything I checked my blood sugars and they were like 14* (mmol/L) *point something. I sort of looked around like confused. Like what's going on? …..I think it was then that they said, 'oh you're on a glucose drip'. I said a 'what? Like a glucose drip'. I'm like, 'well I need to correct for that'. I don't know what the correct rate is for a glucose drip. They didn't even tell me I was on one. They should at least give you a bit of a heads up and I would have done an earlier test* (BGL) *or given a small amount of insulin every so often to cater for it (Eve Int. 9).*

The lack of consideration by the health professional about the impact of a glucose drip on Eve's T1D self-management reinforces the participant's recognition of the health professionals' limited knowledge of T1D management (see 6.2 on page 89). In addition, the action of the health professional further exacerbates the underlying trust issues (see 6.3 on page 100) because Eve was placed in a compromised position, which could have been avoided had someone taken the time to discuss the health professional initiated treatment option with Eve. Overall, having limited discussions with the participants about their T1D in hospital suggested to the participants that health care professionals were not interested in their T1D. These limited discussions further reinforced that the health professionals did not understand T1D management and that they could not be trusted with managing T1D on the patients' behalf when they didn't understand it or showed no interest in it. While the principle of patient-centred care may have been accepted by health professionals in a theoretical sense, collaborative decision-making is not always achieved in reality and this can prevent the person with T1D being able to make a contribution towards shared care decision-making in hospital (Iedema & Manidis 2013).

6.5.2.2 Dietary discussions

Some of the participants experienced concern around the limited discussions they had with health professionals about their specific dietary requirements. As dietary intake is a significant component of self-management of T1D, the hospital system was not taking into consideration how limiting the options the participants had in making their own dietary choices had on BGL and insulin requirements. Clare explained:

> *It would be nice if they told you how carbs are in it* (the food), *because you know they're making these things, hundreds of them* (meals)*, so I would have thought it would be easy to work out per portion of each meal how many carbs. I can't be the only diabetic in hospital that would be interested to know how many carbs. Some people I think who do their injections count in carbs (Clare Int. 2).*

Marie wanted the staff in the hospital to be more aware of what she was eating and why. In response to having experienced limited discussion about her dietary intake in previous admissions, she opted to take her own food to hospital with her so she could make informed decisions around her management as she knew the carbohydrate content of the food. Marie said:

> *That's why I took my own food in because I knew what the carbohydrate value would be and it would make it easier to [unclear] some stuff rather than being presented with food that might not even - that wouldn't be appropriate and I would have no idea what the carbohydrate value of it was either (Marie Int. 12).*

Flanagan et al (2018) suggested that people in hospital with any type of diabetes should have full choice about the meals they are provided with and the carbohydrate content of each meal should be clearly stated on the menu.

Trish had a different experience when accessing a dietitian in a private hospital, as opposed to her admissions in the public hospital system, and had more options to request healthy food choices that matched her self-management requirements. The interactions with the dietitian enabled Trish to appropriately cater for her dietary requirements with her T1D.Trish said:

> *Well, for a start, I had much better control over my diet. I saw a dietitian every single day…. if you wanted to write chicken plus salad, they would cater for that in the private system. There's no ability to cater in the public system (Trish Int. 7)*

For Lucy the only health professional she had interaction with around her T1D self-management during her hospital admission was with a dietitian. She said:

> *They* (hospital) *tried to put me on to a so called diabetic diet. I told them no. I managed it, by bolus for what I ate. Then they weren't happy because I don't like to go over 120 grams of carb a day and so on. I had a fight with her* (the dietitian) *about she didn't want to give me a piece of bacon one breakfast. So I had a fight with her and had a talk to the fellow who ran the kitchen. Then I had another talk with her and told her, look I virtually said 'I use the dosage adjustment for normal eating' (Lucy Int. 1).*

Lucy had to justify her T1D self-management to the dietitian in relation to the diet she was requesting be served.

6.5.3 Discharge planning

During the process of constant comparative analysis during in-depth interviews I recognised that participants were experiencing limited discussions around their T1D with health professionals in hospital. As part of my theoretical sampling I contacted some of the participants via email to ask them whether they had any discussions with health professionals about how they would manage their T1D on discharge or if they might expect any impact on their T1D management as a direct result of the care they had received in hospital (Appendix 18 on page 279).

Laura recalled no discussion occurred with health professionals about managing her T1D on discharge.

> *No one discussed with me anything to do with managing my diabetes after discharge (Laura Int. 6).*

Trish and Bianca both had limited discussions with health professionals' about the management of their T1D on discharge, suggesting to them, that if they had any issues on discharge, then it was up to them to go back to their own diabetes health professionals for assistance. Trish said:

> *The only thing they really said with respect to the management of my overall diabetes when I got home was that if I found myself in trouble with high blood glucose levels or ketones in the 24-48 hours post discharge then I could return at any point via emergency to the hospital. That was really it, no suggestions on how to manage diabetes post discharge (Trish follow up email).*

An Endocrinologist who saw Bianca in hospital suggested that she should consult with her usual diabetes health professional should she experience any issues with her T1D post discharge. Bianca stated:

> *Not really. The endo sort of briefly said once you're out of hospital you consult with your normal endo or my educator (Bianca Int.10).*

Bianca felt confident she could manage her T1D on discharge and knew she could seek help from her own diabetes health professional team should she require support.

> *But I didn't really have any issues but I knew that my endo and my educator were only a phone call away if I needed help (Bianca Int. 10).*

Similarly Trish felt confident she would be able to manage her T1D on discharge as usual without any additional assistance. She said:

> *I did not think I really needed further help at any point once I was discharged, my glucose and ketone levels had returned to pre cortisone injection levels and I felt comfortable and confident to manage myself as per normal (Trish follow up email).*

Harrison et al (2017) identified inadequate discharge planning as being negative for the patient experience and additionally found there is a lack of support for patients beyond their immediate procedure, which can negatively influence chronic condition management. Eve explained why she thought health professionals did not engage in discussions about T1D management at home following discharge. She believed that health professionals possibly do not understand how the episode of hospitalisation actually impacts on a person's T1D management and that after the person goes home their diabetes will not be affected. Eve said

> *….maybe they're* (health professionals) *not fully aware of interactions or changes* (to diabetes) *themselves. Maybe they think it'll* (diabetes management) *just be back to normal, everything will be hunky dory. Whereas you might have an infection or something and you might have a little bit of a resistance from the infection and they might not understand that that can affect the diabetes as well (Eve Int. 9)*

Eve also thought health professionals would need a lot more training to be able to contribute to any kind of discussion about the impact the episode of hospitalisation could have on a person's T1D management once they were discharged from hospital. She stated:

> *I reckon they would need a lot more training. I don't know if they'd be knowledgeable enough to know (Eve Int. 9).*

The participants in the study strongly expressed their need to be included in the discussions with health professionals about how their T1D would be managed in hospital. Larsson et al (2007) suggested that patients have the right to be provided with sufficient information to be able to make decisions in the hospital environment and this information includes how their T1D will be managed. Additionally, health professionals need to take into account what patients with T1D consider priorities in their care in order to meet the patients' needs in hospital (Nordgren & Fridlund, 2001; Florin, Ehrenberg & Ehnfors, 2005). Participants with T1D wanted to be able to actively self-manage or be invited to collaborate with health professionals in regard to their T1D management.

Eve and Jane suggested a strategy health professionals could employ around T1D management in hospital. They said:

> *…perhaps a bit more discussion with you* (in hospital) *about how you might like your diabetes managed rather than it being ignored or not spoken about (Eve Int. 9).*
>
> *….when a person with type 1 diabetes is admitted to hospital somebody needs to sit down and say right what is going to be best for you as far as self-management, and it might be and it might change, it might not be the same thing (Jane FG).*

Patients have been identified as being 'uniquely positioned to provide insightful comments about their care' (Harrison, Walton & Manias 2015). These insightful comments could be used to improve care through inviting patients to contribute to making decisions and choices about their treatment and care in hospital. The participants in the current study live with and self-manage their T1D every day and are therefore in a position to provide information about the care they need for their T1D in hospital in order to keep themselves safe. Castro et al (2016) suggested effective communication with health professionals must occur in hospital and that effective communication with patients can lead to a co-creation of knowledge, rather than the health professional just imparting their knowledge on the patient and vice versa. Health professionals have the opportunity to learn about T1D self-management from people with T1D, as previously discussed in 6.2.3 (see page 97).

According to Castro et al (2016, p. 1929) individual patient participation is about the patient's:

> 'rights and opportunities to influence and engage in the decision making about his (their) care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professionals expert knowledge'.

While this sounds ideal in theory, the lack of communication about self-management of T1D experienced by the participants in the current study left them feeling they needed to take responsibility for managing their T1D with very little, if any, self-reported health professional input.

Overall, the majority of the participants said they did not experience a collaborative interaction with health professionals where strategies concerning their T1D self-management in hospital were discussed and agreed upon. In 1995, Stewart reviewed a number of studies and found there is a significant association between health outcomes for patients and effective patient-centred communication. Further, Neumann et al (2009) found that the use of empathetic communication can advantage both the health professional and the patient, because the patient is more likely to provide more accurate information. Empathic communication can lead to improved long term outcomes because the patient feels valued, understood, accepted and listened to. Participants in the study wanted health professionals to show they were listening to the participant's experience of self-managing their T1D and to achieve some understanding and acceptance of their self-management capacity. Participants would then feel that their experiential knowledge of managing their T1D was valued, rather than being dismissed by health professionals whom they had only just met in the hospital.

Bombard et al (2018) asserted that engaging patients in healthcare has become the cornerstone of quality care. Such engagement has focused on how the patient can be involved in decision-making around their care along with the inclusion of their experiences and expertise to improve and redesign health service delivery. However, Ravenscroft (2010) found participants with multiple morbidities tended to actively make the effort to participate in their care, rather than being supported by the health care system to experience patient-centred care.

Overall, experiencing limited interactions about their T1D in hospital suggested to the participants of the current study that health professionals were not interested in their T1D. Limited interactions are known to lead to patients feeling dissatisfied with the care they receive and to patients constructing their stay in hospital as unsatisfactory (Stoddard 2012) and unsafe.

The lack of acknowledgement from the health professionals generated the perception for the participants that health professionals are dismissing the participants' self-management knowledge and expertise. Furthermore, the lack of discussion about diabetes management in hospital led the participants to believe the health professionals were not valuing their years of lived experience.

Moreover, the participants believed they are a valuable resource of information about managing their diabetes in hospital and felt health professionals did not always take their belief into consideration.. For patient engagement to occur, patients must be able to participate in their care. Health professionals need to recognise and respect the expertise patients have on their own chronic condition and in order for recognition and respect to occur, health professionals need to discuss and understand expectations and goals of care with patients (Oxelmark et al 2018). As a direct result of the health professionals not consulting with the participants about their T1D, the participants were required to rely on their everyday self-management to manage their T1D in hospital and keep themselves safe from harm.

6.6 Chapter summary

Chapter six provided an interpretation of the participants' experience in hospital and their responses to interactions with health professionals, which influenced their T1D self-management construction. The way the participant experienced their hospitalisation and then how they interpreted their experience becomes their constructed knowledge. These *hospital influences on T1D self-management* were driven by previous experiences in hospital and reinforced the participants' perspective that health professionals lack knowledge about managing T1D. The *hospital influences on T1D self-management* led to a lack of trust in the health professionals' ability to manage their diabetes and reinforced trust in their own ability to self-manage. The participants felt that the health professionals were judging whether they could or could not effectively self-manage in hospital, despite showing that they themselves do not understand the self-management requirements of T1D. Overall, interactions concerning T1D self-management in hospital were generally limited. The health professionals acted and the person with T1DM had to interpret the health professionals' actions and then decide what actions they would perform in order to keep themselves safe

The *hospital influences* motivated the person to want to continue their T1D self-management because they were concerned they would be harmed by health professionals' actions. As a result, the participants relied on their *everyday influences on T1D self-management*. The following chapter presents the internal *everyday influences* that the participants relied on in hospital to prevent harm being caused to them by taking actions to keep themselves safe.

Chapter Seven: Everyday influences on T1D self-management

7.1 Chapter overview

The previous chapter focused on the categories external to participants with type 1 diabetes (T1D) that influence their construction of self-management in hospital. In order to prevent harm being caused to them from these *hospital influences*, participants with T1D relied on their everyday self-management to keep themselves safe in hospital. Chapter seven presents the everyday categories that influenced the construction of T1D self-management in hospital; *making contextual decisions, maintaining control, being vigilan*t and *asserting expertise* (see Figure 4 on page 139). This chapter explains how these *everyday influences* are situated within the substantive grounded theory of *Keeping Self Safe*.

These pre-existing *everyday influences* were used by the participants with T1D to protect themselves in hospital from the influences external to them that affect their self-management. These *hospital influences,* as shown in the previous chapter, can cause harm in hospital because they stem from health professionals limited understanding of what T1D self-management entails. These *everyday influences* were viewed by the participants as, facilitators or enablers of T1D self-management in hospital and were empowering. *Hospital influences* (see Chapter 6 on page 88), on the other hand, serve as potential barriers to effective self-management and at times left the participants with T1D in hospital feeling disempowered.

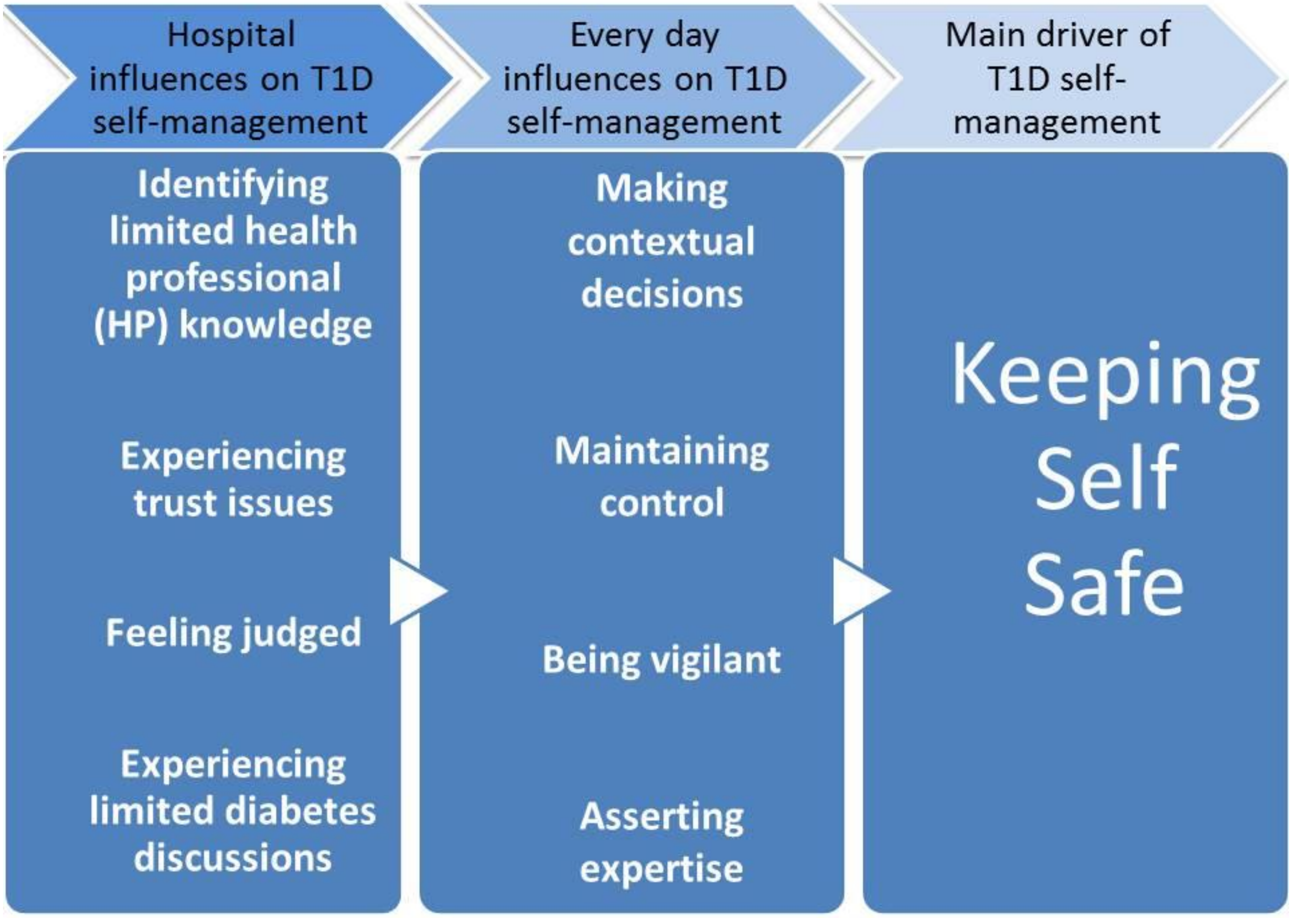

Figure 4: Conceptual model of the substantive grounded theory *Keeping Self Safe*

7.2 Making contextual decisions

Every day, people living with T1D are known to make decisions about their condition's self-management. Wang and Ruhe (2017) described decision-making as:

> '….a basic cognitive process…. by which a preferred option or a course of actions is chosen from among a set of alternatives based on certain criteria' (Wang & Ruhe 2017, p. 83).

The definition suggests people determine the best course of action for themselves by weighing up their options. Entwistle and Watts (2006, p. 274) listed what they believe are the core activities of decision-making:

- Recognition and clarification of the problem
- Identification of potential solutions
- Appraisal of potential solutions
- Selection of a course of action

- Implementation of the chosen course of action
- Evaluation of the solution adopted

In addition to the activities of decision-making, several factors that influence the process of decision-making by individuals were identified. These factors include ‘past experiences, cognitive biases, age and individual differences, belief in personal relevance, and an escalation of commitment’ (Dietrich 2010, p.1). Some of the factors that influenced the decision-making of the participants in the current study included their previous experiences in hospital, the individual requirements of each person with T1D, the belief in their own expertise and their level of engagement in their self-management.

Even though decision-making is a key component of self-management in the current study, the view of this concept is limited within traditional self-management research (Song 2010). However, every day the person living with T1D is known to make self-management decisions in response to the signs and symptoms of their condition without consultation with a health professional (Battersby, Lawn & Pols 2010). As previously discussed (see 1.2.3 on page 3), the number of decisions a person with T1D makes in relation to their diabetes each day is known to be around 100 (Hendrieckx et al 2016). Significantly over 600 tasks that the person with T1D masters in order to self-manage were identified (Coffen 2009; Jull et al 2016). This exhaustive list of tasks, and known number of decisions made every day, suggest there is a significant amount of continuous thought and effort required every day for T1D self-management.

Paterson, Russell and Thorne (2001) identified that T1D self-management involves the person relying upon their past and present experiences, their values and their culture to make decisions about managing their diabetes. In addition, self-management is a dynamic process in which the person reacts to the cues their body is presenting. Further, trial and error occurs in order for the person to discover the self-management strategies that are most effective for them; a form of contextual decision-making (Hernandez et al 1999; Paterson & Thorne 2000). Hence, the person living with T1D inevitably develops a deeply individualised knowledge base about how their body responds in different situations through searching for options, trialling different actions, and experiencing the consequences of those actions (Thorne & Paterson 2001; Kralik, Price & Telford 2010). As Thorne and Paterson (2001, p. 84) acknowledged, the person with T1D makes decisions based on learning ‘how insulin, diet and exercise combine within the unique configuration of a life’ which ‘is a highly complex matter’. The individual therefore develops an experiential knowledge base about what is right for them in different circumstances and bases self-management decisions on their experiential knowledge (Kralik, Price & Telford 2010).

7.2.1 Contextual decision-making at home

All the participants in the study acknowledged the constant contextual decision-making associated with self-managing their T1D. Furthermore, the participants acknowledged how the decisions they make require consideration of a number of factors; contextual to what is currently happening and what could be happening in the future. Dave explained what information he used to make a contextual decision for his T1D self-management. He said:

> *Well, every day I'm basically thinking about maintaining my blood glucose within a particular day depending on the activity that I'm doing. So I am essentially assessing or estimating the carbohydrates that I am consuming. I am matching the doses of insulin to what I assess or estimate the carbohydrate intake to be and I also adjust the dosage* (of insulin) *depending on activity levels and obviously the - whatever my current blood glucose level is at the time that I'm administering the insulin (Dave Int. 11).*

In addition to using available information, such as a BGL, Laura specifically identified that it was her lived experiences with T1D that influenced her to make decisions around her self-management. Laura stated:

> *I guess experience. Having some idea of what I'm going to be doing for the day or for the next few hours. What I planned to eat. If I was going to be in a situation where I didn't have access to insulin,… or to food….(Laura Int. 6).*

For Eve, decisions she made concerning the amount of insulin she would bolus, using her pump, were based on an estimate of the grams of carbohydrate contained in a food she was going to consume. Eve made the decision to bolus only half the required insulin dose for the amount of carbohydrate in a food and then to monitor her blood glucose level (BGL). She would then make the decision to bolus the remaining required insulin based on her body's response to the initial bolus of insulin. Eve said:

> *So I would just - if I think there's 40 grams of carbs in something I'll often just dose for 20 grams and see how I go. Then if you start to rise up* (BGL) *a lot you go, okay, I'll happily bolus for the rest of it now, but you sort of see how it goes and watch it a bit (Eve Int. 9).*

Anticipated levels of activity were also used by participants to make decisions about insulin administration. Bianca stated:

> *The only thing would be if I know that I'm going to be active, you know, I might drop my insulin for half an hour or so, so that it* (BGL) *stays at a decent level. But that's about it really. It's more just you do the tests and then act accordingly (Bianca Int. 10).*

Kate said she made contextual decisions on her T1D self-management based on what her expected level of activity would be in differing areas of her workplace. She stated:

> *Yeah,* (make self-management decisions) *based on what I'm doing. If I'm having a quiet day, a busy day (at work). Because I work in four different sections, so depending on what section I'm in I have to manage my diabetes differently (Kate Int. 3).*

Dave acknowledged that mostly the decisions he makes are the right ones for him at the time although he admitted that there are times when he has things go *wrong* despite making contextual decisions. He acknowledged that self-management is not always 100 percent precise. However, monitoring for major deviations in glycaemic control is always in his thoughts. Dave said:

> *So I'm taking all those things* (activity level, food intake, BGL) *into account in order to determine the dose* (of insulin) *and if things work out, which pretty much most the time it does, everything is fine. Sometimes I get things wrong. So at the same time I'll be looking for major deviations such as hypo or hyperglycaemia and I will take appropriate actions if those events occur (Dave Int. 11).*

The literature suggests that self-management of T1D is not an exact science and sometimes the body reacts differently to what the person expects, despite making the same decisions, in similar circumstances, the previous day (Paterson & Thorne 2000). Paterson and Thorne (2000a, p. 154) explored how people with T1D respond to unanticipated BGLs and found that the decision-making they use can be complex and focused on the cause of the unanticipated BGL, which leads to people making ‘a good guess about how to respond’.

Clare explained how only recently she had recognised how much thinking goes into managing her T1D from discussing her self-management with someone else. She said:

> *It wasn't until recently someone said something and I realised how much it (TID self-management) does affect every single thing I do in the day. You know if I want to go for a walk I have to do a blood test and work out if I'm too low to go for a walk or too high to go for a walk or you know that kind of thing; just everything….anything you want to eat, anything you want to drink, you've got to do a blood test and tell your pump (Clare Int. 2).*

In addition to recognising the contextual decision-making that occurs continually in T1D self-management, the participants acknowledged this process becomes second nature over time and subconscious. John and Bianca explained how their decision-making blended into the background of their daily lives, becoming almost ‘second nature’ despite being constantly necessary. Dave stated:

> *….the actual management, yes, there's an enormous amount of thinking going into it but it's kind of like background thought to me now. It's almost like - it's like breathing. You don't think about….You're thinking - you're kind of thinking about it because every now and then you go - you take a bit of a deep breath in and you recognise you're doing it. But it, it's much more background for me now, the management side of it. It's there constantly, it's always there, but it's not a stressor anymore (Dave Int. 11).*

Bianca said:

> *I think I constantly make decisions but because it's been so long (since diagnosis of T1D) it's kind of just second nature now….Yeah. I just sort of, you do it but not, you know, most of the time not a lot of thought goes into it. It's just automatic (Bianca Int. 10).*

Similarly, Clare recognised that a significant aspect of her T1D management occurs at a subconscious level but at the same time, she often wondered what it would be like to have a day off from, or even be cured of her diabetes. Clare stated:

> *So yeah all through the day it is constantly on my mind but it's kind of subconscious because it's just what I do, but then just occasionally you think I'd like a day off doing all*

> *that. If I got cured I guess that's what it would be like and I wouldn't know what to do with myself (Clare Int. 2).*

Participants explained how their subconscious mind allowed them to manage their out of target range BGLs. For Lucy, eating additional biscuits without thinking led her to recognise she needed to monitor her BGL. Lucy said:

> *You've got to know what you're doing, which then again after 50 years at that stage, I knew what I was doing. You learn to listen to your body. I mean, I know there are times when I just go and get a sweet biscuit or something and end up eating three of them, and thinking why am I doing this. Going and testing* (BGL). *Right, yes, that's a bit low (Lucy Int. 1).*

While for Kate, having some unexplained hyperglycaemia led her to recognise that symptoms of a potential chest infection were affecting her BGL. Kate stated:

> *Usually when I've got high blood sugars I know its stress or something's going on in my body. Like over the weekend I had highs and I'm thinking, this isn't right! My asthma was playing up and now I feel like I've got a chest infection so I'm off to the doctor today…. I just know how to do corrections and up my insulin, and know what to do (Kate Int. 3).*

Participants acknowledged contextual decision-making as being significant for people with T1D because *there are no two diabetic people in the world that manage their condition the same way* (Dave Int. 15) so people therefore, need to make self-management decisions that are contextual to them and their T1D.

7.2.2 Decision-making in hospital

While the participants were making contextual decisions every day out of hospital, they were also making decisions while in hospital utilising the same decision-making processes they used at home. When in hospital contextual decision-making continued based on their strong trust in themselves to self-manage and their previous hospital experiences, which incorporated decisions made during their previous hospital experiences. Prior to their involvement in the current study all participants had previously experienced an admission to hospital, and in some cases for the same admission diagnosis. Therefore, participants could anticipate in their most recent admission, how being in hospital would influence or impact on their diabetes management whilst maintaining their own individualised diabetes targets.

Participants in the study recognised the need to consider some additional factors in hospital such as the impact of certain medications or the influence of surgical procedures on BGL. Therefore, they were making decisions that were contextual to their hospital experience and their usual T1D self-management. Dave and Nicola explained some of the additional factors they are aware of that can influence BGLs in hospital. Dave stated:

> *I've got the advice of doctors saying after the operation generally with diabetes you have this spike* (increased BGL). *It's like the same if you are put on steroids. You're going to have to increase your basal* (insulin) *dose. You just know these things and you adapt it to the situation (Dave Int. 11).*

Nicola added:

> *….we know we're going to go in* (to hospital), *we're going to be put under an anaesthetic, we know that we're going to usually have pain at the end of it, we're in a foreign environment, they've changed our diet, they've limited our mobility and those sorts of things, and that's stressful enough anyway (Nicola Int. 4).*

Therefore, before even going into hospital, participants were taking into consideration previous hospital experiences, which they used to construct their future experiences of T1D self-management in hospital.

During Clare's most recent hospital admission she required the administration of Methylprednisolone to manage the symptoms associated with her primary admission diagnosis. Clare discovered the significant impact the medication had on her blood glucose levels and through trial and error with her pump she managed to reduce her BGL back to her target range. Clare said:

> *…the steroids they gave me to get the feeling back in my arms, Methylprednisolone I think it was, something like that, oh my goodness that sends your blood sugar levels through the roof. I had to put my pump on 200 per cent after I realised. The first time I'm just doing corrections every like 10 minutes to try and get my blood sugar levels down. I was in the twenties* (BGL)…..*so that was just crazy trying to fight my blood sugar levels (Claire Int. 2).*

When questioned further Clare could not recall any health professional discussing the affect the medication would have on her BGL and the expected need for additional insulin. Ravenscroft (2010) explained that health professionals and health care systems tend to focus on conditions in isolation from one another, and so do not address the interactions of one condition on the other. Such siloed thinking by health professionals does not take into account the workload and effort required by the person with T1D to maintain their diabetes targets while other conditions in hospital influence their BGLs. For the participants in the current study, their T1D was managed in hospital due to their active engagement 'rather than the results of the system which supported patient centred care' (Ravenscroft 2010, p. 222). Clare relied on her own knowledge from previous experiences with elevated BGLs and trial and error, rather than input from the health professionals, to make appropriate decisions to manage her elevated BGLs. She stated:

> *…. I worked out what was going on so I just hit my pump to 200 per cent which seemed to work it out for those three days (Clare Int. 2).*

Similarly Trish recognised the need for individualised contextual decision-making for effective T1D self-management that was outside the usual parameters when managing ketones (definition of laboratory ketonaemia is <3 mmol/L (Dunning 2014). Trish experienced an episode in hospital where she recognised she *had all the symptoms of quite severe ketones* (Trish Int. 7). Trish explained:

> *I'm severely nauseated. I've got chest pain....I get really severe jaw pain, quite bizarre, but I said 'I've got all the symptoms of ketones* (ketoacidosis)*, and if we don't do something quite quickly, I'm going to be vomiting' (Trish Int. 7).*

When Trish monitored her blood ketones they measured 0.4mmol/L. Through previous experience, Trish recognised that if her ketones reached 0.5mmol/L she would be in trouble and would require additional insulin to prevent ketoacidosis[11] (Trish Int. 7). The health professionals required some convincing that Trish was experiencing ketotic symptoms[12] because she was not meeting the generalised parameters for measuring ketosis. Yet Trish relied on her own contextual decision-making to prevent diabetic ketoacidosis (DKA) from occurring. She said:

> *….so I was asking them to put the IV back on at a blood glucose level of 13* (mmol/L)*, but I also had two arrows on my continuous glucose monitor going straight up. So I've got two*

---

[11] Diabetic ketoacidosis, related to hyperglycaemia, is a life threatening condition which can be experienced by people with T1D

[12] Symptoms of ketoacidosis include excessive thirst, excessive urination, nausea and vomiting, abdominal pain, weakness, sweet acetone breath and increased respiration, confusion.

> *arrows. I've got it alarming and I'm in trouble. I need the IV, and I need more than one unit* (of insulin) *an hour (Trish Int. 7).*

Thorne stated (2008), expert patients recognise they have their own unique T1D manifestations and there is not a one size fits all approach to self-management. These unique manifestations allow and require people with T1D to make contextual decisions about their diabetes. Participants in the study recognised the irrationality of population norms, known as text book management, and were able to disregard scientific evidence as they recognised they don't fit the usual diabetes management mould (Thorne 2008). Trish explained her unique manifestation with her response to ketone levels in her body and the difficulty her response causes with a health professional who does not know her. She stated:

> *Because I don't think that I fit the norm, like at 0.5 ketones, I'm struggling. Like I don't think I've ever - I think I've seen ketones of three once, and I would be seriously comatose at three, and I've seen people running at higher than that and still able to have a conversation (Trish Int. 7).*
>
> *So, it's….why even to have a visiting endocrinologist* (in hospital) *makes it difficult. It's fine for an endocrinologist to say, do this and this, but that just doesn't work.... I've had those experiences before where you have an endocrinologist that doesn't know me, that will come in and tell me to do this and this, and that just doesn't work, and never has (Trish Int. 7).*

Kate experienced elevated BGLs in hospital that she recognised were direct results of the timing of the nurse performing the blood glucose monitoring (BGM). By using her contextual decision-making she was able to identify that the BGL was not a true reflection of her glycaemic control. Kate explained:

> *They were charting stuff in their charts and I also had my log book there, doing stuff. So, when I had a visiting endocrinologist come, she just looked at it sort of thing. She said to the nurse that if I went over a certain level* (BGL) *to ring her and notify her. I knew a few times they'd tested I'd eaten a meal so of course I'm going to be high. So I'm like, 'look girls don't worry, my blood sugar will come down and I'll be okay' (Kate Int. 3).*

Eve acknowledged that health professionals in hospital may not understand the intricacies involved in making decisions in relation to T1D self-management. She stated:

> *They might not understand the intricacies involved. They might say, oh okay, so you're 5.5* (mmol/L) *and you're about to eat a bread roll, so how much insulin would you give? You'd be like well is my CGM trending down or is it trending up or am I going to be sitting here for the next two hours? All these sort of different things. There's a lot more involved (Eve Int. 9).*

Lucy could identify that a suggestion of management of insulin by health professionals would not work for her by relying on her contextual decision-making. Lucy said:

> *….we are going to titrate this* (insulin) *and do that and you are thinking well that is not going to work (Lucy Int. 13).*

What is evident from the participants is that health professionals need to acknowledge diabetes self-management is more than just a prescriptive regime. Participants wish that health professionals would support the stance whereby the individual living with diabetes 'is indeed the most reliable and accurate source of information about his or her physiological function' (Paterson & Thorne 2001, p. 87; Visekruna, Edge & Keeping-Burke 2015). Furthermore, people with T1D want recognition of their knowledge and ability to manage their chronic condition and their responses to their condition when they are admitted to hospital (Munt 2009). However, the participants in the current study reported that there was a lack of recognition by health professionals of the contextual decision-making that allowed them to effectively self-manage their T1D. The study participants believed that the focus of the health professional was to only document information required by the chart. As explained by Trish:

> *They would come in and ask me how much insulin I'd given myself….On occasion, just to write it in the chart…. But quite often I would be doing blood glucose levels, five and six and 10 times more than they would actually write on the chart and giving them, because I was constantly dosing, constantly to try and get those blood glucose levels down. So I would be giving insulin after the two-hour mark or the four-hour mark when my pump was set. Every half an hour, my insulin pump would suggest an insulin dose (Trish Int. 5).*

Trish recognised that health professionals were missing information for their chart due to her frequent BGM and constant dosing of additional insulin. As a result, health professionals were missing documenting all the doses of insulin Trish was self-administering. Furthermore, the effort

Trish required to manage her BGLs using her contextual decision-making was unknown to the health professional.

Self-management decision-making requires ‘an increasingly sophisticated and integrated capacity to weigh alternatives, make choices, attend to evidence, listen to one’s unique body cues and develop an individualized system by which to know whether one is doing better or worse over time’ (Thorne 2008, p. 11). Thorne (2008, p. 11) suggested that the person living with T1D requires attention to meet the needs of their chronic condition ‘within the inherent complexity of relational and contextual changes’ and the challenges presented by these complexities throughout their life.

As a consequence of using contextual decision-making at all times to self-manage her T1D, Nicola felt she would choose not to go into hospital should her decision-making be taken away from her in the hospital. Nicola said:

> *If they took that* (T1D self) *management and those decisions away from me, I probably wouldn't go in, unless it was life-threatening or whatever. Because I've been managing my diabetes for such a long time now, I don’t believe that anyone is going to know more about how my body works than me (Nicola Int. 4).*

The participants deferred to their default position of making contextual decisions to self-manage their T1D self-management as there had been no opportunity to discuss their preferences for care of their T1D (see 6.5 on page 121). As a result of these limited discussions the participants were left to make decisions and continue their usual self-management in hospital in order to safely manage their T1D. In addition, the lack of trust in the health professionals in hospital, along with the identification of limited health professional knowledge of T1D management, as discussed in Chapter six (see 6.2 & 6.3 on pages 89 & 100), were also highly influential in the choice to continue contextual decision-making to self-manage T1D in hospital.

7.3 Maintaining control

The term *control*, when used in relation to diabetes management, tends to suggest the person with diabetes is responsible for their diabetes self-management while also indicating the person is following the advice of the knowledgeable and authoritative health professional (Dickinson et al

2017). Broom and Whittaker (2004) suggested that for people living with any type of diabetes the word ‘control’ can mean two things. First, control in diabetes management can be linked to the biomedical language of health professionals against which people living with diabetes are judged; for example, ‘control’ of their BGL. Diabetes Australia (2016) published a position statement for health professionals on the use of language around people with any type of diabetes. They contend that the word ‘control’ infers a moral judgement by health professionals on the person living with diabetes and they state that:

1. many factors outside the persons control influence BGLs,

2. continually aiming to achieve or maintain control can lead to negative feelings if control is not achieved or maintained,

3. BGLs may be influenced by the person with diabetes but maybe never truly controlled (Diabetes Australia 2016, p. 5).

The other meaning of control for people living with diabetes relates to their desire ‘to assert a positive identity and agency in the management of their disease’ (Broom & Whittaker 2004, p. 2381). The ideal of ‘being in control’ is a highly valued trait in society and it suggests the individual who is in control has power and agency as opposed to the chaos, madness and moral failing traits that are linked to being out of control (Broom & Whittaker 2004; Dickinson et al 2017). Charmaz (1987) described taking control of the ‘disease’ and its treatment is a way of separating one's identity as an ill person from other personal and social identities, to maintain a sense of normality. Ingadottir & Halldorsdottir (2008) found that having self-control was an important trait that enables a person to situate diabetes self-management into their life.

For the participants of the study, maintaining control was often linked to their own individual BGL targets while in hospital. Yet it also meant being able to maintain control of their self-management in hospital, which was pivotal to their independence and safety. Maintaining independence through self-management facilitated a sense of control because they didn’t want to feel out of control because that conflicts with their normal construction of their daily life. People living with T1D want to continue to manage their diabetes to the best of their ability with the tools and resources available to them and through relying on their contextual decision-making.

Wellard (2010) suggested that self-management is a strategy used to empower people to be in control of their chronic condition. Participants in the study self-reported they were actively engaged in their T1D self-management and normally felt in control of their daily management out of hospital. They had all achieved a sense of mastery over their T1D self-management through years of contextual experience living with T1D, taking their sense of mastery to hospital with them.

7.3.1 Being in control at home

Paterson and Thorne (2000) explained being in control of T1D as being able to mediate the effects of the chronic condition so the individual could live their life with normalcy. Those living with T1D describe their evolution into experts in self-managing as tantamount to assuming control of their condition (Paterson & Thorne 2000).

For the participants in the current study the drive to be in control of their T1D commenced at a young age. Ingadottir and Halldorsdottir (2008) suggested that personality and personal characteristics play a role in being independent, having control and situating diabetes in an individual's life. For Lisa, learning how to be in control of her condition started at diagnosis and continued into adulthood, through her taking ownership of her T1D. Lisa stated:

> *I suppose cause my parents very much from the day I was diagnosed have said to me this is your condition, you will have to manage it for the rest of your life because we will not be here as parents to be able to hold your hand and walk you through life. So I learnt very quickly to deal with most things by myself as a child, then I suppose through camp we were always taught to look after our own diabetes, that you have to look after it. I suppose through becoming a RN and seeing how diabetes is managed in a hospital you then would think good god these people can manage themselves so that reinforced my need to be able to look after myself and then I've always wanted to. I felt better that I was doing it, I know myself, I know my body, I know how my insulin works so I felt very protective of myself...that only I can do it (Lisa FG).*

Similarly, Dave decided early on that he was going to take control of his T1D and that his condition would need to live with him, rather than him needing to live with his condition. He said:

> *I made a decision very early on in my life as a person living with diabetes that diabetes would have to live with me. I'll respect it but it's going to have to live with me. That kind of turned everything on its head (Dave Int. 11).*

According to Thorne (2008) people with chronic conditions often determine that they must have agency and authority in their lives, and this often leads to them becoming experts in the self-management of their chronic condition.

Clare also discussed how she claimed control over her diabetes and now recognises how much control she actually has since being diagnosed with MS, a condition over which she believes she has no control.

> *When I got diagnosed with the MS that's not something I can control. The diabetes I can. If something goes wrong generally it's because I've done something wrong or miscalculated something. It* (T1D) *is within my control and I've said, oh my goodness since I could speak for myself really, that I would not let this disease control me, I would control it and I wouldn't let it stop me doing anything….(Clare Int. 2).*

Trish acknowledged that while her T1D does not control her, it does play a role in influencing decisions she and her family make, especially when selecting a place to go out for dinner. She said:

> *While it* (T1D) *doesn't control me or it doesn't dictate, it certainly influences a lot of the decisions myself and the family make (Trish Int. 5).*

Marie recognised that she currently is in control of her T1D because she is meeting her BGL targets and she is not experiencing hypoglycaemia due to the increased self-management control she has recently adopted. Marie explained:

> *I take complete responsibility for my disabled pancreas, so I do blood testing and modify my diet, do lots of blood testing, modify the insulin I'm using. I've got really good control and I'm not getting any lows (Marie Int.12).*

Through respecting their chronic condition, these participants are able to self-manage and maintain wellness and they are aware of the consequences of not self-managing, which can be life threatening. Paterson and Thorne (2000) developed the term ‘active control’ to explain the final phase in the development of self-management expertise. The final phase demonstrates diabetes has been integrated into the person’s life, and that the person has assumed control over their self-management. Kralik et al (2004) supports that self-management is about taking control over one’s life. In addition, ‘active control’ is also about the recognition of being able to live a normal life as a result of having attained this level of self-management control.

However, some participants recognised that constantly being in control and managing well can be tiring. Clare acknowledged that maintaining control of her diabetes, especially in relation to self-managing a pump, sometimes leaves her wanting a day off from being in control. She said:

> *You do hit your lows with it and I have days where I wish I wasn't diabetic and I just wish - sometimes, especially with the amount of control I have to do with having the pump really - after the pump - doing all the blood tests and all that, sometimes I just would like a day off; just not to have to worry about it, think about it (Clare Int. 2).*

7.3.2 Being in control in hospital

All participants expressed that they wanted to remain in control of their T1D by self-managing their diabetes while in hospital. Paterson and Thorne (2000) acknowledged that people with T1D develop the desire to have control over decision-making in parallel to the development of their expertise in their diabetes management. All participants in the current study explained that they chose to maintain control because they believed they had sufficient knowledge to manage their T1D and felt that health professionals did not have the same level of knowledge about their diabetes (see 6.2 on page 89). In addition, being in control of their T1D in hospital is associated with the lack of trust they have in health professionals in hospital to safely manage their T1DM, coupled with the absolute trust they have in their own ability to self-manage.

The participants in the study identified they made expert decisions and were actively engaged in controlling their T1DM through their self-management. Jane and James recognised their need to maintain control in hospital because of their expert knowledge of their bodies that they had developed over a number of years of living with T1D.Jane said:

> *…. it is our bodies and we know what works for our bodies and we have to be able to say this is what I need and not be told by somebody who doesn't know our particular bodies what to do (Jane FG).*

> *….well I feel that I am competent enough to manage my diabetes 'cause I have told them I have been doing it a lot longer than you have been alive (James FG).*

Similarly, Clare acknowledged she was the 'best person' to manage her T1D in hospital and recognised that the health professionals did not have the same level of knowledge about her T1D.Claire stated:

> *I think I'm the best person for it. I'm the one who knows my body. I know my diabetes. I know the kit, so yeah. I mean I know like nurses and doctors are medical people but they're trained in either specific fields or very general fields, not necessarily me and my diabetes (Clare Int. 2).*

Clare also identified that she felt confident she could maintain control of her T1D in hospital because she had access to all the equipment she needed to maintain control of her BGLs; for example her BGM, her insulin and her pump. Clare said:

> *Confident is the first word that comes to mind* (to self-manage T1D in hospital). *Because I know what I'm doing and I have everything within my control…So yeah I guess everything* (diabetes equipment) *was within my grasp and within my control (Clare Int. 2).*

As well as an overall confidence to manage their diabetes, Lisa and Trish wanted to maintain their T1D self-management while they were in hospital for surgical procedures. Lisa expressed she wanted to continue to be responsible for her T1D by choosing to inform the surgeon she was able to maintain her self-management. She said:

> *I informed my surgeons that I am quite capable and confident of doing that* (managing diabetes) *(Lisa FG).*

Similarly, Trish felt able to continue to self-manage her T1D and indicated that this was her preferred option for the management of her condition while in hospital following surgery.

> *…all of my surgeries have been about me managing my own diabetes in hospital…most of mine has been about the fact that while I am quite comfortable to do that, and would much rather do that (self-manage) (Trish FG).*

However, the participants recognised that always being in control of their T1D in hospital was sometimes challenging. Susan experienced an emergency admission to hospital where she had a loss of control of her self-management due to not having access to the equipment she needed to self-manage. Susan's efforts to maintain control of her T1D were hampered by the hospital not being able to provide her with the insulin she needed to self-manage, something she found frustrating. Susan stated:

> *Well twice I have ended up in hospital through emergency, ambulances, and I don't have my stuff with me and trying to tell them I need an* (insulin) *injection...'Oh we don't have Lantus or I wonder if we can get that' and 'oh excuse me I am still waiting for the Lantus' and off they go again so I find that very frustrating. I know I nearly always have everything but the other day it was 10 o clock at a vet appointment and I didn't realise I was going to collapse there and then…. so that is completely out of your realm if you don't have everything with you all of the time (Susan FG).*

Furthermore, there was recognition by some of the participants of the impact of being in hospital on glycaemic control. Lisa identified how her body reacted to being in hospital despite the attempt she made to maintain control of her BGL. Lisa had learnt to accept her body's response would be out of her control for a couple of days. She explained:

> *….but the day of surgery I start extremely low* (BGL) *despite whatever I've done the night before hand and as soon as I walk into the hospital my sugar levels go through the roof and will not come down but throughout the actual anaesthetic they come down which is great and then once I'm awake they start to climb up again so I have this high low because I just know it is my body's response because I've lost that control and my body's adrenaline is pushing out cortisol which is making my sugar levels go up so I am just fighting the whole time to get my sugar levels down and then I get them down and I crash and then they go back up again. That's my body. So despite whatever plan is there it doesn't really work anyway and that's ok cause I can live with that for those couple of days I'm going to be in hospital (Lisa FG).*

Ingadottir and Halldorsdottir (2008, p. 615) acknowledged that people do have an underlying intention 'to do their best to control their diabetes' but that it is not always possible. Lisa acknowledged that once she was out of the hospital environment, she knows that she will be able to regain and maintain control over her glycaemic levels. She said:

> *….I know as soon as I get home I'm in control again and it's my environment, my body then will settle down 'cause I am back in my own bed, shower, house, husband is nearby, family is nearby I can call upon (Lisa FG).*

Marie identified she felt vulnerable in hospital specific to maintaining glycaemic control to achieve optimal outcomes. She stated:

> *But my concern is that you're most vulnerable when you're in hospital in the first place. That's when you want the* (glycaemic) *control to be the best it can be so that your body's in a position to deal with whatever else the problem that you're in hospital in the first place for (Marie Int.12).*

Lucy concluded that there are some conflicting thoughts in hospital between health professionals and the person with T1D about who is in charge of the person's T1D management. Lucy said:

> *It's control of something* (T1D management) *that you know what you are doing….when you are confronted with someone* (health professional) *who wants to change what you are doing, it really is a matter of who's going to have control.... The Doctors seem to think 'oh no we are in charge'....They* (health professionals) *think they are in charge but they are not….. (Lucy Int. 13).*

7.3.3 Being unable to maintain control

Castro et al (2016) suggested patients experience a feeling of powerlessness when they lose control over their bodies. For the participants in the current study losing control of their T1D was a frightening prospect, especially as they perceived they had control of their diabetes out of hospital as well as having little confidence in the health professionals being able to safely manage their T1D on their behalf. The participants in the study indicated being in control of their T1D self-management gave them some power in hospital as a patient. Dave explained he felt his control was taken away from him in hospital.

> *If you tell me I'm going into hospital the first thing I fear is fear....because obviously my very early experience is the control is taken away from me….as doctors will want to do things their way. So I would avoid, in the past I would avoid hospital like the plague. I would have to be near dead before I would go to hospital and that is how much I would be reviled and fearful of doing that* (going to hospital) *(Dave Int. 11).*

Participants felt that if they were unable to physically undertake self-management tasks, they would still want to maintain their involvement in their self-management by making management decisions in consultation with health professionals. Dave had considered how he could continue to be involved in his insulin administration even if he was unable to see. He said:

> *If I couldn't see for instance I could still feel the clicks on the pen but I couldn't read my CGM - yeah, the nurse came in and said 'oh, your CGM is this - what dose do you think you should take' and....I just say 'well let's look at the estimates, carbs, rah, rah' 'yeah, do this'. I would still want to be engaged in my management (Dave Int. 11).*

Similarly Trish felt that if she was too unwell to manage her BGM she would still like the health professional to allow her to decide about whether she would maintain control or not. She said:

> *If I'm unwell enough that I am unable to even finger prick, I would like them to be able to give me the choice. 'So, do you feel well enough to do it?' 'Actually no, do you know what? I don't.' Or, 'do you feel that you're okay to manage?', 'Actually, yes I am' (Trish Int. 5).*

Potential loss of T1D self-management control led some participants to express panic and concern. Kate indicated she would panic if she was not in control of her T1D in hospital because she viewed herself as usually always in control. Her response to losing control suggests that an important part of Kate's construction of her T1D self-management was to maintain control. Kate stated:

> *I think I would freak out….If I'm not keeping in control....I've always been in control* (of my T1D) *(Kate Int. 3).*

Eve recognised that she would feel immediate concern for her health should she not be in control of her T1D in hospital. She believed that the health professionals would not have sufficient time to be able to provide appropriate management especially if her BGLs were out of target range. Eve indicated that the potential for inappropriate management of her T1D would lead her to feel frustrated by the situation. Eve said she would be:

> *Very frustrated and I would immediately worry about my health. I just don't think that they* (health professionals) *would be able to manage it* (T1D) *the way I would. Especially because nurses are busy. They don't have time to check in on me every half hour and just look at the CGM and ask how I'm feeling because I can feel pretty yucky if I'm going low. Then if I was high and maybe if I called them and it took them ages to respond I'd be really antsy to be giving a correction* (dose) *and knowing that I couldn't do that would make me*

> *feel really frustrated that I'm not getting the best care and stuff. So yeah, it would really, I'd be really pissed (Eve Int. 9).*

Maintaining control over T1D self-management in hospital was driven by the participants' belief of being the one who knows their body best, which was previously discussed throughout this thesis. Bianca stated:

> *….but you know your own body, you know what's best sort of thing and I just, I wouldn't like handing over the reins to someone else….I don't mind* (self-managing T1D in hospital). *It's just like any other day I suppose. I'd rather it be in my control than someone else telling me what to do (Bianca Int. 10).*

In response to the possibility of having to relinquish control in hospital, some of the participants discussed strategies they have in place to keep themselves safe in hospital. These strategies involved their family members being required to contact their usual diabetes health professionals for instructions and then the families taking control of the T1D management on the participants' behalf. Eve explained:

> *So yeah I've sort of given family instructions and things if I'm unconscious to maybe get in contact with my diabetes educator or someone. They can maybe be taught what a safe practice would be and that kind of thing (Eve Int. 9).*

Eve's indication of preferring her family to be taught by her diabetes educator about how to manage her T1D on her behalf suggests a lack of trust in the health professionals in the hospital to manage her T1D, because they are not her first choice to manage her T1D.

Lisa explained that the ability to maintain control of her T1D self-management was possible for a planned admission to hospital. However, she would be concerned about her capacity to have control over her T1D self-management in hospital if she were admitted as a result of an emergency. Lisa said:

> **....***I suppose I have always been lucky 'cause my surgery has always been planned so I have that control. I have this fear if I get caught up in an emergency, what hospital would I get taken to and what the hell would actually happen to me and I have a fear of that, so I always make sure my family would say right we need to get in touch with Lisa's Endocrinologist right now, and she is going to get on the phone and talk to you right now, she will give you some advice on what you should be doing right now. So I actually have my*

> *Endocrinologist phone number and my husband has it and he knows he can use it if the emergency situation comes about (Lisa FG).*

Similar to Eve, Lisa had instructed her family to contact her usual diabetes health professional for instructions on how to manage Lisa's T1D if she was unable to self-manage her diabetes in hospital. So, while Lisa indicated it was easier to maintain control in a planned admission, she has a plan in place for an emergency admission to keep her safe in hospital with her T1D.

7.4 Being vigilant

Being vigilant has previously been linked in the literature to those who self-manage a chronic condition. Niedel et al (2012, p. 252) described vigilance as 'watchful attention, with maximal readiness to detect and react to the….symptoms'. Being vigilant can assist those with chronic conditions to recognise the potential warning signs for future health related problems (Kralik et al 2007; Knaster et al 2011) and enables people to adjust their activities to avoid becoming overwhelmed or unwell (Murray et al 2011). Kralik et al (2004) suggested that self-management, by its nature, leads to the person being vigilant about their body cues to their condition along with planning daily activities. Therefore, being vigilant could be viewed as a person's primary behaviour strategy for day to day self-management and a way of maintaining control of their chronic condition (Riegel & Carlson 2002).

Being vigilant in relation to T1D management is mostly found about parents in the literature, in particular mothers, managing children with T1D. Sullivan-Bolyai et al (2003) found that mothers managing the day to day management of children with T1D recognised the need for constant vigilance. The need for constant vigilance emerged from concerns about the day to day management of their child's condition. These concerns included the potential long term complications along with the need for ongoing assessment of the competence of others who may provide care for their children (e.g. child care, babysitter) (Sullivan-Bolyai et al 2003).

Soltesz (2003) suggested that parents face the need for eternal vigilance in response to the never ending demands of T1D. Niedel et al (2012) found that parents develop parallel vigilance through knowledge and experience of managing a child with T1D. Parallel vigilance enabled parents to protect their children through normal childhood development, while also being watchful for the specific manifestations of T1D (Niedel et al 2012). Furthermore, parallel vigilance enabled parents to evaluate their child's symptoms, integrate information they had and then make informed treatment decisions for their child (Niedel et al 2012).

As children become more independent with their self-management of their T1D, it would be reasonable to conclude that they would take on the role of being vigilant in their day to day management through to adulthood. While there is a lack of existing literature concerning being vigilant for the adult living with T1D, the participants in the study identified the need to be continually vigilant to self-manage their condition each day, in and out of hospital.

7.4.1 Being vigilant everyday

Paterson and Thorne (2000) explained that adults living with T1D become vigilant through learning about their diabetes, listening to their bodies and through the experience of daily self-management. Those living with T1D have the ability to tune into their bodies and have determined effective individualised management strategies through experiencing a variety of management decisions over time (Paterson & Thorne 2000a). Being vigilant allows people living with T1D to monitor their body's responses to a chosen intervention, to determine the effectiveness of the intervention and to identify whether the intervention could be effective in the future when faced with a similar circumstance (Paterson & Thorne 2000a). As a result, those who are vigilant to their body's responses are known to be competent self-managers (Paterson & Thorne 2000a).

The participants in the current study acknowledged the underlying need for everyday vigilance for self-managing their T1D. Dave and Lucy recognised that being vigilant is a requirement of living with and managing T1D. Dave stated:

> *I think…. vigilance is what we do anyway (Dave, Int. 11).*
>
> *By nature we are vigilant, we have to be (Dave Int. 15).*

Lucy explained:

> *It's* (T1D) *24/7, it's 365 days of the year, you don't get a holiday, you don't get paid, you don't get long service leave (Lucy Int. 13).*

Lucy acknowledged the extent of being vigilant every day by explaining that T1D is not something you have a break from and therefore neither is being vigilant around T1D self-management. Lucy added that the consequence of not being vigilant while living with T1D could mean life or death (Lucy Int. 13). Similarly, Trief et al (2013) recognised that constant vigilance is required by people living with T1D in order to protect themselves from the potential dire consequences of hypoglycaemia, such as seizures and coma.

7.4.2 Being vigilant in hospital

All participants brought everyday vigilance to managing their T1D to hospital. Being vigilant in hospital had two components. Initially, participants attempted to be as prepared as possible for their admission to hospital in order to be able to successfully continue their self-management. Once in hospital the participants were vigilant in order to protect themselves from harm that could be caused to them in the hospital environment. The underlying need for the participants to protect themselves had developed through previous hospital experiences, due to recognising the health professionals' limited knowledge of T1D (see 6.2 on page 89) and consequently lacking trust in health professionals (see 6.3 on page 100).

7.4.2.1 Being prepared

Participants discussed how they attempted to be proactive and establish a plan to support their T1D self-management in hospital in an attempt to prevent becoming unwell. On occasions there was no opportunity for a face to face pre-admission appointment, which influences the ability to prepare for an admission. Similarly, a pre-admission appointment online does not facilitate being able to adequately prepare for T1D management while in hospital. Despite these barriers the capacity to prepare for admission was ingrained in the participants due to their ability to rely on their everyday vigilance in managing their T1D.

Some participants initiated their preparation for admission to hospital contacting their usual diabetes health professionals. Bianca contacted her Endocrinologist prior to her planned admission to hospital in order to prepare for her hospitalisation. Bianca said:

> *I rang the office and let him* (Endocrinologist) *know because he had mentioned to me earlier if you ever have surgery you need to let me know (Bianca Int. 10).*

As a result of Bianca phoning her Endocrinologist prior to admission, he was able to organise another Endocrinologist to visit Bianca in the hospital she was to be admitted to because he did not have visiting rights there. She explained:

> *….he* (Endocrinologist) *organised for an endo to meet me in the hospital and for them to be on call if needed (Bianca Int. 10).*

Kate was also proactive prior to her planned admission and made contact with her Diabetes Educator. Kate stated:

> *Yeah I had different scenarios worked out with the educator, what to do* (in hospital) *(Kate Int. 3).*

Participants being admitted to hospital unplanned did not have the opportunity to pre-prepare for their hospitalisation. Dave experienced an emergency admission so planning his T1D management in hospital was about establishing a relationship with the Doctor once admitted and then establishing a plan. He said:

> *I first of all try to form a relationship with whichever doctor is there because that's the first step in management, is if I can convince that person that I can manage my diabetes and I'm happy for them to take over if I can't, then we usually have that common ground and everything is fine (Dave Int. 11).*

Another aspect of being prepared for hospital for these participants was to ensure they had the necessary equipment required to self-manage their T1D in order to maintain their everyday vigilance. Examples of the required equipment include BGM and strips for the monitor, specific insulin they had been prescribed and insulin pump consumables[13]. Clare and Eve stated that the equipment they would take to hospital would be essentially the same as the equipment they would have with them for *going anywhere* (Clare Int. 2). Clare said:

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[13] Insulin pump consumables include the cannula and tubing and the reservoir. The cannula is inserted subcutaneously for 2-3 days and the tubing connects cannula to the pump reservoir. The reservoir is a cartridge that holds the prescribed insulin changes every 2-3 days (Diabetes Australia 2016a).

> *….so I would have made sure I'd got insulin with me and the cannula change, all those bits. Blood tester kit and enough blood testing strips. Yeah that would probably be about it. That would be all I'd need really* (to continue self-managing) *(Clare Int. 2).*

> *Well I always go everywhere with my little kit. I've got my meter, I've got a pen so I can inject if something happens to my pump for any reason and it has hypo treatment in it as well, so I just carry that everywhere I go (Eve Int. 9).*

Both Clare and Eve knew they could always rely on their husbands to bring additional equipment to manage their T1D in hospital if required. Clare stated:

> *….because I didn't know how long I was going to be in* (hospital) *but I had to just assume I could be there for ages. I also knew that my husband would be coming down* (from the country) *within so many days to visit me, so if I needed any more goodies he could bring them down. So I made sure I'd got enough for you know the first few days that I was definitely going to be on my own (Clare Int. 2).*

For Eve, living close to the hospital, she knew her husband could *jump back* and go home and collect any additional equipment she needed to manage her T1D (Eve Int. 9).

The participants knew from previous experience of not having access to equipment to self-manage in hospital to take their own equipment into subsequent admissions. Through being prepared, the participants were able to be ready for any possible scenarios that may occur in hospital and to be able to act on those scenarios. Hypoglycaemia management was expressed by the participants as an issue in hospital and they took steps to protect themselves from the harm of hypoglycaemia by taking their own food. Kate stated:

> *I took hypo food. I actually took my own food in there, for if I needed snacks or something (Kate Int. 3).*

> *I always do* (take own hypo treatment food). *I always take biscuits and lollies (James FG).*

James had learned through previous experience to not only take his own food, but to keep his food hidden in his bag so it was not confiscated by health professionals. Confiscation of food would leave James in a situation where he could not react to hypoglycaemia symptoms he had detected.

Overall, the participants were attempting to maintain control over their T1D in hospital by being prepared through ensuring they had access to the equipment they needed to self-manage, as they would have every day at home. Despite experiencing limited discussions with health professionals prior to admission to hospital (see 6.5 on page 121), these participants were ensuring their safety by bringing the equipment to hospital that they would require to be able to continue their self-management.

7.4.2.2 In hospital vigilance

The participants in the study monitored their T1D just as they would do every day out of hospital. This pattern of monitoring helped ensure their T1D management was within their individual target range and not out of their control (see 7.3 on page 149). Furthermore the participants monitored what was happening around them in relation to their diabetes management in hospital. Ravenscroft (2010) found patients with multiple co morbidities within the health care system undertook the same kind of monitoring and kept watch over the care they were provided in hospital. Similarly, parents of children with T1D are known to assess the competence of those people around them who provide care for their children through being constantly vigilant (Sullivan Bolyai et al 2003).

Dave acknowledged that he was vigilant in hospital and the level of vigilance he needed varied according to the type of treatment he received from health professionals. He stated:

> *It* (level of vigilance) *certainly doesn't change in the hospital* (compared to home), *if anything it heightens a little bit depending on how you are treated in the hospital. You are going to have to watch how they are doing things in order to make sure you are ….keeping yourself safe. You are wanting to make sure they don't deliver your insulin 30 minutes before any carbs arrive 'cause you know you will fall through the floor (hypoglycaemia). Absolutely being vigilant is definitely appropriate (Dave Int. 15).*

When questioned about whether hyper-vigilance was required in hospital Dave explained that as he was mostly self-managing his T1D hyper-vigilance was not required. Dave said:

> *I wouldn't say that it was a huge increase on my vigilance* (in hospital) *(Dave Int. 11).*

Dave also acknowledged that his level of vigilance around his T1D self-management may increase when in hospital due to the potential of being judged by health professionals. He stated:

> *....we* (people with T1D) *feel like we're going to be judged* (by health professionals) *on our blood glucose. So do we increase our vigilance to deal with that? Probably…. I made a point*

> *that I'm going to manage this* (T1D) *until I can't. So yeah, I put in little bit of extra effort to make sure that no one thought that I couldn't manage it.... (Dave Int. 11).*

Feeling judged has previously been discussed in 6.4.1, which included the feeling of being judged as incapable based solely on BGLs.

Prior to her surgery Susan insisted on managing her own insulin injections because she knew if she did not, she may miss injections, which would impact on her T1D. The evening prior to her surgery Susan experienced 'a low' and had her 'own sugar tablets' because the hospital could not provide the food she needed as the kitchen had closed. Susan knew that in order to protect herself from harm on the day of surgery, in the form of hypoglycaemia, she needed a glucose source because she had administered her insulin injection and had not yet been commenced on any intravenous fluids pre-operatively. Susan explained:

> *The anaesthetist came in the morning and said 'um how you going?" well I've had my injection, I said 'I'm going to run low if I don't have something', 'cause I was doing all my own injections 'cause I refuse to miss them, 'oh have some lemonade, that will be alright'. So he* (the anaesthetist) *gave me some lemonade and I checked* (BGL) *before I went down* (to theatre) *that I was alright and I said 'can you please make sure that I am ok when I come out' (Susan FG).*

Post-operatively Nicola experienced a need to be vigilant in hospital due to the symptoms she was experiencing coupled with the consequent response of a health professional who Nicola spoke with about her symptoms. Nicola (Int. 14) stated she *felt dry mouthed so decided to check her ketones*. When the nurse entered Nicola's room she explained *I am just letting you know I have checked my ketones and have got a 0.4 of ketones* and the response of the nurse was *she literally waved at me and backed out the door* (Nicola Int. 14). The nurse did not return to Nicola's room, so Nicola stated she needed to be vigilant in hospital as *I do not want to go into DKA and die in this hospital* in response to the incident (Nicola Int. 14). Nicola also chose to contact a health professional external to the hospital for support on her decision to check her ketones based on the symptoms she was experiencing post-operatively as the response of the nurse was confusing to her.

Nicola also explained she is aware that *more people go into DKA in hospital than anywhere else* (Int. 14). Watts and Rayman (2018) indicated that 1 in 25 people with T1D in the United Kingdom

(UK) will experience hospital induced DKA due to insulin under treatment by health professionals. Furthermore, 2200 people with T1D in hospital in the UK in 2017 were known to have experienced DKA in hospital through no fault of their own with no change in the rates of DKA experienced since data collection began in 2011 (Health and Social Care Information Centre (HSCIC) 2018). The UKs National Diabetes Inpatient Audit of 2017 also found that 1 in 4 people using insulin in hospital, including those with T1D, experienced a severe hypoglycaemic event, which required injectable rescue therapy to manage (HSCIC 2018). The collected data from the UK demonstrates the risks people with T1D face in hospital from missed care from health professionals. The risk of harm may explain why the participants felt the need to be vigilant to remain safe. Nicola also acknowledged that while people with T1D try to remain vigilant in hospital it is not always easy due to the impact of anaesthetic and pain relieving medication. She said:

> *We try and be vigilant while we are in hospital, but we can't always do that (Nicola Int. 14).*

Ravenscroft (2010) similarly had a participant state that they felt fretful around recognising there may be some instances where they may not be able keep track of what is happening around them, such as if they are unconscious. Being unable to keep track of their chronic condition management leads people to worry about what could potentially happen if they are not able to be vigilant about the care they receive from health professionals. Laura explained her concern about not being able to maintain vigilance should she not be able to self-manage.

> *Nothing terrifies me more than the idea of being in a hospital or a nursing home unconscious with somebody else controlling my insulin (Laura Int. 6).*

The participants in the study remained vigilant not only to maintain control over their T1D but also to ensure health professionals were not going to do something that could jeopardise the control they had over their BGL, possibly leading to harm. Sutton, Eborall and Martin (2015) found that patients assume the role of 'vigilant monitor' of the care they receive from health professionals, this being the patient's way of being involved in their own safety while in hospital. In addition, Rainey et al (2015) found that patients in hospital are vigilant for any objective threats to their safety, which includes medication errors such as those experienced by participants in the current study in relation to their insulin. By using their everyday self-management expertise, the participants were maintaining their safety by being vigilant about their T1D management.

7.5 Asserting expertise

In this thesis, specifically the literature review (see 2.8 on page 30) and throughout Chapter seven (see 7.2 on page 139), it has been recognised that people living with T1D develop expertise in managing their condition through years of lived experience. Prior (2003, p. 53) supported the idea that patients are ‘experts by virtue of having experience’ in the use and expression of knowledge in particular contexts and circumstances. In addition, Wellard (2010, p. 7) stated patients have expertise in their ‘specific experience of their illness, their social situation, the levels of risk they are prepared to accept, their own values and preferences for living and treatment choices’. People living with diabetes develop self-management expertise by learning what works best and through the development of body awareness (Hernandez et al 1999: Paterson & Thorne 2000a; Ingadottir & Halldorsdottir 2008). Therefore, every day people with T1D rely on their expertise of self to make contextual self-management decisions.

However, while in hospital the participants in the current study made contextual decisions grounded in their everyday self-management expertise in response to the interactions they had with health professionals. During these interactions participants recognised the limited health professional knowledge of T1D (see 6.2 on page 89) and their response was to assert their T1D self-management expertise to keep themselves safe from unnecessary harm. Furthermore, through being vigilant (see 7.4 on page 159) about what is happening around them in hospital, the participant with T1D was able to assert their expertise in response to the actions of health professionals. Sutton, Eborall and Martin (2015) found that patients are speaking up as a consequence of feeling unsafe, which matches the experience of the participants in the current study, and consequently leads to their decision to continue to self-manage their T1D in hospital. Therefore, asserting expertise for the participants in this study was about using previous knowledge to advocate for themselves by fighting for, or negotiating care to keep safe (Mackie, Marshall & Mitchell 2018).

7.5.1 Overt assertion of expertise

The participants needed to assert themselves in hospital due to the judgements they received from health professionals about their level of expertise and capacity to self-manage. Some participants in the study indicated that they asserted their expertise in response to not wanting to be judged as incompetent. Both John and Lucy expressed the need to not be judged negatively by health professionals. In order to not be judged they needed to assert themselves or fight with the health professional to have their expertise heard and validated. John said he asserts himself in order to demonstrate that he is engaged in his T1D self-management. He said:

> *Asserting expertise is certainly what engaged people do….we want to be recognised that we are not complete idiots here (John Int. 15).*

While Lucy stated:

> *With non diabetes health professionals you get the feeling they don't trust you so you need to fight with them to get them to think you are not an idiot (Lucy Int.13).*

Within the hospital environment there are discourses that are reinforced through society and institutional values as well as beliefs and values (Griscti 2016a). These discourses consequently privilege the expertise of health professionals over the patients. Health professionals are seen to have scientific rigor to support their actions, which the lay person is seen not to have (Griscti 2016a). However, people living with T1D develop their own expertise in everyday self-management decision-making (Thorne 2008). This expertise develops over time and usually occurs through informed strategic experimentation with symptom management or creative variation from medical recommendations when managing T1D (Thorne 2008). Such expertise developed by people with T1D can be viewed by health professionals as being 'non-compliant' or as failing to adhere to the recommended medical approach to condition management (Thorne 2008). Wellard (2010, p. 7) suggested that 'both levels of expertise and perceptions of that expertise vary among patients and professionals.' What became clear in the current study was that the participants were using their previous experiences both from home and in hospital, and their knowledge from years of lived experience, to assert their expertise and make informed decisions in their most recent hospitalisation to keep themselves safe. Dave explained:

> *They came in at the start and said ‘okay, we're going to do this’ and I said ‘hmm, I don't like the sound of that’. I got into quite an argument with….the orthopaedic registrar and he said ‘yeah, we're going to put you on a continuous drip where we're going to titrate insulin and glucose in these ratios’. I said ‘those ratios are wrong. I want you to use this’. He said’ no, we're the doctors’. I said ‘no, I'm the - I am the person with diabetes here and I know my management’ (Dave Int. 11).*

> *It took a while to get to the person above him who I said ‘if I can't control it you guys take over. But until the point where I can't control it I want to be in control’. This guy, he ummed and ahhed a bit and then he said ‘yeah - well actually, you're looking pretty good. So yeah, we'll go with that’... (Dave Int. 11).*

People with chronic conditions want to be acknowledged by health professionals as experts of their chronic condition experience. They have their own values and preferences for how they manage their T1D and the levels of risk they are prepared to accept around their T1D management. In order to build successful health professional and patient/consumer partnerships, the expertise of the person with T1D needs recognition. An area of diabetes management where the participants’ expertise was not considered by the health professional related to insulin pumps. Participants were therefore left to assert themselves in order to keep their insulin pumps while in hospital. Trish said:

> *….I know my rights, and sometimes I probably am a little bit righteous in that, but I say, ‘no, I'm sorry, my insulin pump stays with me, that's what keeps me alive, you have to work around that’. ….there's a misunderstanding that the minute you hit a hospital, you must be removed from your insulin pump, and I have objections to that (Trish Int. 5).*

Similarly Kate stated:

> *When I went in for my operation they were like, we’re taking you off your pump and we’re going to do everything. I’m like oh no, no, no it’s not going to happen (Kate Int. 3).*

Another area in which participants felt the need to assert themselves was around the misconceptions of the health professional about dietary requirements. Lucy explained:

> *I objected to having diabetic put down on the menu that would come around and sort of being told what I should eat. I thought bugger you. I don't do that at home, why should I do it here? I know what I want to eat. Yes, I'll have the occasional piece of cake but I don't eat it every day. They were saying to me ‘you're not eating enough at breakfast’ and trying to give me extra stuff. I'd just send it back. It was a waste. (Lucy Int. 1).*

There was a perception among the participants that health professionals did not always appreciate their assertiveness around their T1D self-management. However, they also identified the need to not be aggressive around issues related to their diabetes management as being aggressive is not a socially acceptable behaviour. Lucy explained the art of being assertive when she said:

> *.... it's important to be, not aggressive, but you have to push the fact that you can do it (Lucy Int. 1).*

The flipside to asserting one's T1D expertise, was not wanting to be viewed and labelled as a difficult patient. Individuals' interpret social situations and respond in a way that is deemed appropriate in order to draw the desired response from others involved in the interactions (Byrne & Heyman 1997). For example, the participants with T1D in the current study were respectfully challenging and politely disagreeing with health professionals to assert their expertise. However, they were mostly being polite and respectful in order to achieve their desired outcome of being able to continue their T1D self-management and to keep themselves safe. Patients are known to refrain from pointing out issues they have identified to health professionals because they do not want the quality of care they receive to be impacted on, through being labelled as a trouble maker or as difficult (Berry et al 2017). Therefore, there is a balancing act for the patients to manage the conflict of asserting themselves to prevent potential harm being caused to them, while being mindful of not impacting on the quality of their care through being labelled as a difficult patient. Berry et al (2017, p. 1375) described this balancing act as a manifestation of hostage bargaining syndrome which:

> *'may manifest in inner turmoil between speaking up or remaining silent, between assertiveness and inaction. The hesitation may even escalate to fear of saying much of anything at all. This risk is especially great when patients must advocate for themselves'.*

Marie experienced limited interactions with health professionals prior to her surgery and as a consequence no one informed her of the delay to her surgery. The lack of information sharing impacted on Marie because she missed out on her required basal insulin dose. Marie also recognised that she did not speak up about the need for more basal insulin pre-operatively because she did not want to be labelled as a difficult patient. She explained:

> *....I didn't speak up* (about the missed insulin)*. I should have been more assertive but I didn't want to be difficult....I just felt like there was no point to make any more trouble otherwise I'm going to be classified as difficult and I didn't want to make things more difficult for myself. I didn't care about them really. You know, it's just human nature that if you've got someone that's being a bit difficult, you're less likely to be helpful when you're under pressure and you've got to prioritise and stuff. I'm trying to be intelligent about how I got through this (Marie, Int.12).*

Another downside to asserting expertise is being judged as refusing treatment despite just attempting to have an open discussion about their T1D management in hospital. Dave said:

> *I had to go above his head and I had to say - he said 'oh, you're refusing treatment?' I said 'I'm not refusing treatment. I am consulting with you on how my treatment is going to be done' (Dave Int. 11).*

Trish believed that by asserting her objection to being removed from her insulin pump she was setting herself up for being viewed as non-complaint by the health professional. Trish stated:

> *That sets the scene then, because you're deemed to be a non-compliant, because I will challenge them - respectfully, but I will challenge them. Some people are okay with that, but most health professionals don't like to be challenged (Trish Int. 5).*

Brashers, Naas and Neidig (1999) suggested that patients reject treatments, or are willing to be non-adherent, when treatment fails to meet their expectations. They are not actually being deviant, but they are making reasoned decisions based on their treatment choice drawn from their beliefs, responsibilities and preferences and their expertise. Raising concerns, if they are worried, is the way patients can be involved in their own safety (Sutton, Eborall & Martin 2015).

Dave offered a different perspective of being seen as being difficult and not complying and that is that he is actually engaged in his T1D self-management. He explained:

> *Well I - look, I'm deliberately non-compliant. There's no doubt about that. Yes, to a person who thinks in that way I'm a deliberately non-compliant. To my endo I am engaged (Dave Int. 11).*

7.5.2 Advocating for self

The participants in the study expressed the need to advocate for themselves in hospital through relying on their expertise. The participants reported that they felt the need to express to health professionals how they would prefer to manage their diabetes or what they needed to do to manage their diabetes in order to keep safe and well. For example, maintaining BGL within individualised target range or insulin doses based on needs, or anticipated needs, depending on what is happening at the time. The participants expressed that if they did not speak up and advocate for their own diabetes management then there was not someone who would be able to do so on their behalf. Moreover, often there was a conflict between what the health professional recommended and what the participant’s years of lived contextual experience suggested. Lisa, a health professional, felt she had practised advocating for patients in her care and could consequently use those skills to advocate for herself.

> *….I think because I have to so many times advocate for my own patients at work that I tend to then do it for myself so ‘why?’ ‘how come?’ ‘what for?’ ‘when’s this going?’ ‘why are you doing that now?’ So I actually ask the doctors that are going to do the surgery on me ‘are you sure about that? what’s going to be the outcome of that? what are the side effects of that? how many people have you done this on before?’ I am doing this for myself and if you don’t know the answers to these questions then I want you to go away and find out the answers for me. That’s what I do for my patients at work. If they have asked me a question and I don’t know the answer then I will go out and find it for them. So yes I think….because we have that medical understanding and we have a disease which we have to constantly know about what’s going on we tend to do a bit more so….if people do have type 1 that are quite happy to go ‘yes doctor’ ‘no nurse’ ‘ok then’ you think good god what sort of management do they get in hospital (Lisa FG).*

Trish suggested *losing your voice* occurs in hospital when you are in the patient role and as a health professional herself, she wondered how those who are not familiar with the health system manage to advocate for themselves (Trish FG).Trish said:

> *Yeah, it's a double-edged sword. Because it* (being a health professional) *increases your expectations, but also there's the knowledge of knowing that you don't have to say, yes, just because that's what you've been told. You are allowed to say, no, and you are able to say, no, I'm not coming off my insulin pump, because that's the option that I choose, and you're going to have to work around that. Whereas someone who doesn't know the system, would just go, oh okay, that's what the doctor said, and that's what I have to do (Trish Int. 5).*

Feeling protective and being in control of themselves forced the person to advocate for them self even when they were not a health professional. The reason for self-advocating was to protect themselves from harm and to represent their own interest in any decision-making around their T1D management in hospital. Participants want their knowledge and expertise recognised by the health professional and they don't want their decisions about their T1D self-management to be dismissed. Ravenscroft (2010) suggested people with comorbidities in hospital are actively advocating for themselves through asking questions. Furthermore, people are voicing their opinions or concerns to health professionals and on occasions directing the health professionals about their care requirements (Ravenscroft 2010). The requirement to speak up is essential to overtly keeping safe in hospital.

The participants in the study did listen to the health professionals suggestions for T1D management in hospital and considered their recommendations. Participants then anticipated what would potentially occur if they followed the health professionals' recommendation by using their contextual decision-making. The participants then relied on their previous experience when they anticipated what the outcomes of following the health professional's advice will be for their T1D. As a result of using contextual decision-making, the participants could make an informed decision. They then inform the health professional that if they follow their advice what they believe the outcome will be. From this point, they can then provide their alternative action.

Participants asserted their expertise by informing health professionals what their preference for management was, while ensuring they could justify their actions to the health professionals. Justification is required in response to the health professional not consulting initially with the participant with T1D about their preferences of care. Additionally, the health professionals may not accept the individuals understanding of what they anticipate will happen to their BGLs in hospital. Overall, the participants in the current study were making reasoned decisions based on their management choices drawn from their expertise, priorities and preferences (Brashers, Haas & Neidig 1999; Ravenscroft 2010).

While they advocated for themselves in hospital through asserting their expertise, the participants were also advocating for others with T1D. Lucy wrote a letter of complaint to the hospital following her discharge. One aspect of her complaint was the health professional’s refusal to monitor Lucy’s ketones. Lucy believed she was experiencing symptoms of ketoacidosis however, the health professional suggested Lucy was not *sick enough* to warrant ketone testing (Lucy Int. 1). Lucy was aware that writing the letter would not alter her experience but she felt she was advocating for others who could be in the same situation as herself in the future because she hoped her letter would lead to improvements in care for the person with T1D in hospital.

Another aspect of advocating for themselves, and others with T1D, was to inform and potentially educate health professionals about how a pump or continuous glucose monitoring (CGM) works (see 6.2.3 on page 97). Nicola identified knowledge deficits in health professionals about the impact of steroids on BGLs. When Nicola was admitted to hospital and administered steroids she had a CGM to monitor her BGLs. Nicola printed a copy of her CGM results for her Doctor so he could then show future patients what may be an expected response to steroid treatment. Nicola explained:

> *What I did, I actually printed out in colour my CGM overlay for that week. So that he can show his patients, this is what will happen to your sugars when I give you this steroid injection. Because the doctors will say, ‘just keep an eye on your sugars’, but they don't tell the patient exactly what's going to happen, and then their sugar* (blood glucose) *levels are in their 30s* (mmol/L) *and then they go, ‘oh, what do I do now?’ (Nicola Int. 4).*

However, participants suggested that they needed the health professionals to show interest in what they were doing to manage their diabetes and not just wipe their hands of any responsibility if the person stated they would self-manage their diabetes in hospital.

7.5.3 Covert assertion of expertise

Insulin administration was another area in which the participants indicated that they felt the need to protect themselves and sometimes ‘lie’ to the health professionals to keep themselves safe. Not being listened to lead the participants to do their own thing and not consult with the health professionals about their self-management decisions. Participants experienced hospital admissions where health professionals removed self-management equipment from them. As a result, participants learnt for subsequent admissions to hide their self-management equipment from the health professionals so they could access their insulin, BGM and hypoglycaemia supplies when needed.

Another example of participants being covert was their responses to a diabetes management suggestion by a health professional, in order to protect themselves. Trish knew through her lived experience that if she followed the health professional's order her BGL would elevate because she was under stress. The Doctor suggested that Trish reduce the pump basal rate and Trish indicated she would follow the order however she left her basal rate unchanged. Trish stated:

> *I wasn't going to change my basal rate or reduce it by 10% and I just went 'got it' and she went 'ok'. So she wandered off as happy as Larry after giving me the instructions (Trish, FG).*

Participants are therefore making contextual decisions about their T1D management in hospital but choosing not to discuss these decisions with health professionals due to their perception that health professionals lack knowledge about T1D (see 6.2.1 on page 90). Therefore, by being 'deliberately non-compliant' they are actually taking considered actions to keep themselves safe in hospital (Scibilia 2017).

Castro et al (2016, p. 1924) asserted that patients are being recognised 'as experts on their own bodies, symptoms and situations'. For the participants in the current study, despite relying on their experiential knowledge to make contextual decisions to manage their symptoms, they still had to assert their T1D self-management expertise to health professionals in hospital in either an overt or covert manner. Such assertion of expertise was not only a way to keep themselves safe from harm, but was the only way participants could demonstrate their in-depth understanding of their body's response to illness. The assertion of expertise was also required because most participants were not involved in discussions with health professionals about their T1D management prior to their admission to hospital or early in their episode of hospitalisation. In order for health care to truly become more patient-centred, participants must be invited to actively participate in decisions about their care, especially when the experiential knowledge of the person who self-manages their T1D every day is far greater than the knowledge of the health professional (Castro et al 2016).

Participants in the study had to assert their expertise due to having limited opportunity to discuss their T1D management with the health professionals. Participants reported that they had no prior opportunity for negotiation of their care with the health professional. Lucy said:

> *…. I think it would be nice to be asked and nice to work out something* (a plan of care) *before you go in so you don't have to have fights with people (Lucy Int.1).*

The lack of two way conversations maintained the health professional as dominant, therefore they would propose a treatment option that the participants would then assess, leading to a contextual decision being made. As part of this decision-making the participant decided whether the recommendation by the health professional would keep them safe or expose them to potential harm. Participants felt they needed to assert their expertise to keep themselves safe as their responses were not always accepted by the health professionals who viewed themselves as the expert. Lack of consumer-centred care, shared decision-making and patient participation in care led to the participants with T1D having to assert their expertise to protect themselves from harm in hospital.

7.6 Chapter summary

Chapter seven provided an interpretation of the participants' everyday self-management construction and how they relied on it in hospital. The *everyday influences on T1D self-management* were used as a default in response to the *hospital influences*. Participants relied on their contextual decision-making for T1D self-management in hospital, especially as they were often left to manage their T1D without any health professional interaction. There was also a requirement for participants to assert their T1D expertise due to the limited knowledge of health professionals and their lack of recognition of the individualised requirements of those with T1D. Consequently, the need to be vigilant was evident as was the strong desire to maintain control of their T1D in order to not feel out of control to reduce the risk of harm being caused to them while in hospital.

The following chapter presents the substantive grounded theory of *Keeping Self Safe* that was constructed through the data explored in both Chapters six and seven. Chapter eight examines the relationship between the internal and external influences on self-management for the person with T1D in hospital and how these influences were the main driver for *Keeping Self Safe*.

Chapter Eight: The Social Construction of Keeping Self Safe

8.1 Chapter overview

The aim of the study was to explore the experience of type 1 diabetes (T1D) self–management in hospital with the purpose being to construct a substantive grounded theory using Charmaz's (2006; 2014) constructivist grounded theory (CGT) method. These experiences included the actions and meanings the participants with T1D assigned in constructing their experiences of self-management in hospital. The theory is, therefore, an interpretation of the phenomenon, which was co-constructed to form an overall understanding of T1D self-management in hospital.

The two previous chapters presented the conceptual categories of the substantive grounded theory, which were *Hospital influences on T1D self-management* (see Chapter 6 on page 88) and *Everyday influences on T1D self-management* (see Chapter 7 on page 138). This chapter will focus on the core category of the substantive grounded theory, *Keeping Self Safe*, and will also detail how this new theory adds to existing knowledge of T1D self-management in hospital.

8.2 Constructing the substantive theory

As explained by Charmaz (2014) the term theory is not always clearly defined among grounded theorists. As previously discussed in Chapter three, Charmaz (1990) identified a weakness in the use of grounded theory when researchers possess a lack of clarity of key terms in the method, such as the term theory. Thornburg and Charmaz (2012, p. 41) defined theory as 'relationships between abstract concepts' with the aim being to provide an explanation or understanding of a phenomenon. The theory constructed in the study demonstrates how the abstract concepts in the conceptual model (see Figure 4 on page 179) link together to explain the participants' experience. Charmaz (2014, p. 344) stated that a substantive theory is a 'theoretical interpretation or explanation of a delimited problem in a particular area'. In the study, the substantive theory is an interpretation of the problem, which is T1D self-management, and the particular area is the hospital. As the study is located in an interpretive paradigm, the theoretical understandings have been generated through my interpretation of the experience of T1D self-management in hospital, which is grounded in the participants' construction of their reality (Charmaz 2014).

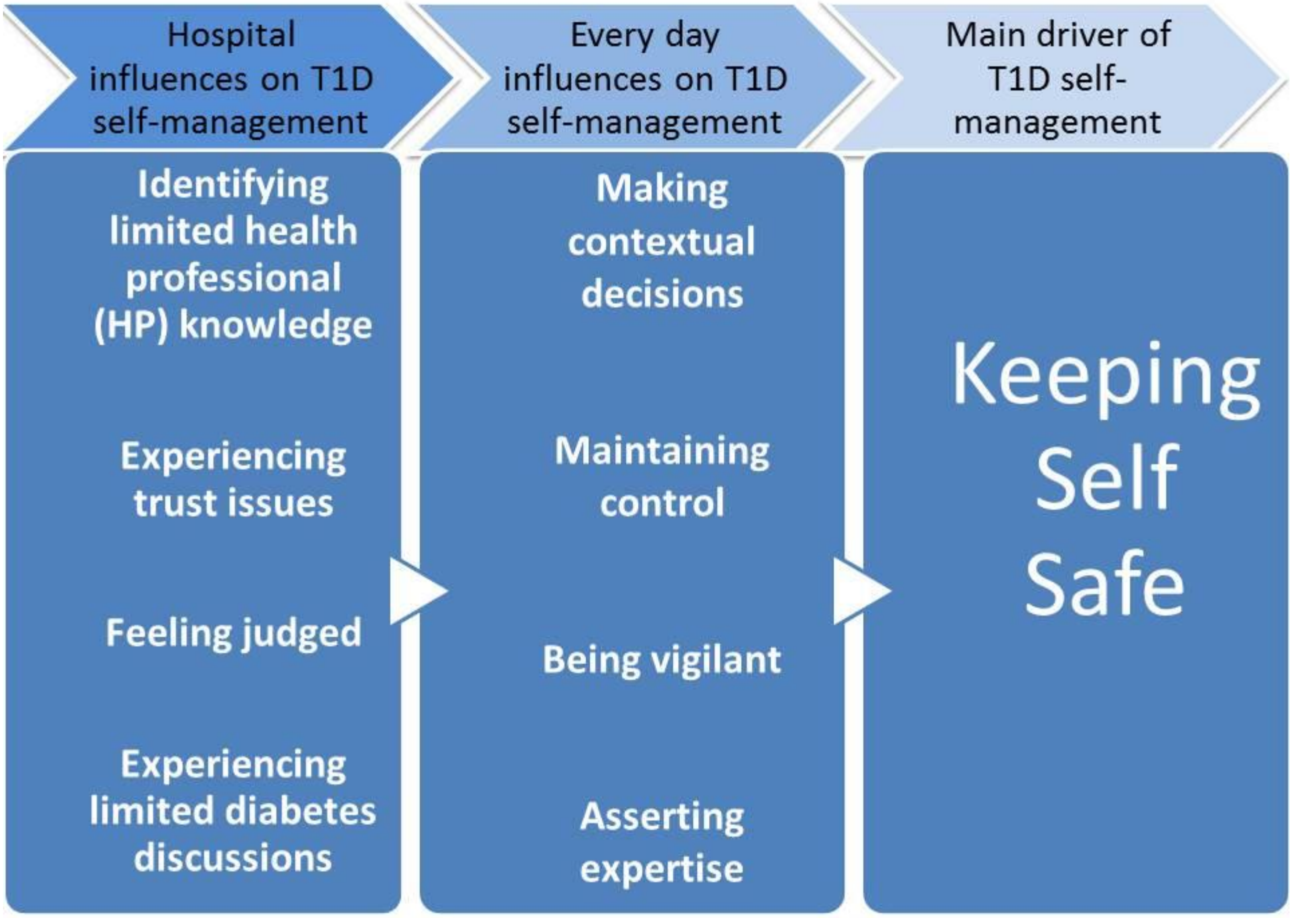

Figure 4: Conceptual model of the substantive grounded theory of *Keeping Self Safe*

The conceptual model demonstrates how the participants responded to the *hospital influences on T1D self-management* through the use of their *everyday influences on T1D self-management*, with their actions being driven by the need to keep themselves safe in hospital. For example, the participants relied on their everyday contextual decision-making to make informed self-management decisions in hospital. The main impetus for *making contextual decisions* was participants' recognition that health professionals did not have the capacity to make contextual decisions for the participants T1D. Furthermore, there were limited opportunities to discuss and develop plans of care for T1D management in collaboration with health professionals. Hence, the participants relied on their everyday self-management to keep their T1D within their normal target range while in hospital, to remain safe.

8.3 The core category of Keeping Self Safe

Strauss and Corbin (1990, p. 116) stated that the core category is the ‘central phenomenon around which all the other categories are integrated’. Birks and Mills (2011) added to this statement by suggesting the core category is a concept that encapsulates a phenomenon, which is apparent in the categories of a grounded theory and the relationship between the categories. Charmaz (2006) indicated a broader approach to the integration of the categories to form an ‘abstract grounded theory of a substantive area’.

During the constant comparative analysis of the data, initial codes and focused codes were raised to a conceptual level and then raised to the theoretical level of the core category (Charmaz 2014) (see 4.6 on page 65). The core category was named *Keeping Self Safe* because it captures the underlying internal response the participants had to the numerous hospital and everyday influences that shaped and constructed their experience of T1D self-management in hospital. The core category therefore captures the actions and interactions experienced by the participants in the study, who were motivated by the need to keep themselves safe in hospital and were relying on their everyday T1D self-management practices in order to do so.

8.4 Defining Keeping Self Safe

The expression of *Keeping Self Safe* was not identified in the research or grey literature as an existing term. Participants in the study were motivated to maintain their safety for survival and to prevent harm being caused to them by health professionals. Therefore, the decisions participants made and the subsequent actions they carried out in hospital were driven by a basic human need. Maslow’s Hierarchy of Needs refers to the notion of safety to keep people safe from harm, which includes personal security and health (Maslow 1943). Maslow (1943) recognised the need for safety as being the second most important category in the hierarchy of needs, following physiological needs, which must be met for human beings to continue to function. Maslow’s hierarchy of needs highlights the importance of safety to meet the basic needs of humans (Maslow 1943).

The terms keeping safe (predominantly around child protection), keeping yourself safe (prevention of being a victim of crime) and keeping patients safe (see 8.4.2 on page 184) were located in the literature. However, these terms do not completely represent the core category of *Keeping Self Safe* in the context of self-management of T1D in hospital.

I have used the following definitions from the English Oxford Living Dictionary (2019) to construct a definition of the term that is relevant to the subject of this thesis. *Keeping* is defined as 'the action or fact of owning, maintaining, or protecting something' (English Oxford Living Dictionaries 2019). *Self* is defined as 'a person's essential being that distinguishes them from others, especially considered as the object of introspection or reflexive action' (English Oxford Living Dictionaries 2019b). *Safe* is defined as being 'protected from or not exposed to danger or risk; not likely to be harmed or lost' (English Oxford Living Dictionaries 2019a). Hence, within this thesis, *Keeping Self Safe* can be defined as the individual taking action in order to protect themselves from danger or risk so that they are not likely to be harmed. This definition supports the underlying actions of the participants in the study. *Keeping Self Safe* was a priority to the participants because it is what they practice every day at home and they took these ingrained practices with them to hospital in order to remain well. In addition, participants believed that the health professionals did not have the time or sufficient knowledge of their T1D to keep them safe. These beliefs were core to why the participants wanted to maintain control of their self-management while in hospital.

There were a number of variations of the term *Keeping Self Safe* identified in the literature that are relevant to the discussion of the substantive theory. The similar terms included patient safety in healthcare, patient involvement in their own safety, and making hospitals safe for people with diabetes. These terms are discussed in more detail below (see 8.4.1, 8.4.2 & 8.4.3 on page 181, 184 & 186).

8.4.1 Patient safety in healthcare

The Institute of Medicine (IOM) released a seminal report titled *To Err is Human: Building a safe health system,* which provided some alarming statistics about medical errors in American hospitals (Kohn, Corrigan & Donaldson 2000; WHO 2010; Groves, Meisenbach & Scott-Cawiezell 2011).

Two studies, one conducted in Colorado and Utah, the other conducted in New York, found that adverse events were occurring in hospital. A number of these adverse events had led to the death of patients, with over half of the reported deaths known to have been preventable (Kohn, Corrigan & Donaldson 2000). The two studies found that more Americans were dying as a result of medical errors each year[14] than were dying as a result of motor vehicle accidents, breast cancer or AIDS (Kohn, Corrigan & Donaldson 2000; WHO 2010).

As well as the numbers of reported deaths, there were also significant financial costs associated with preventable adverse events, which led to lost income, lost household production and health care costs to treat the results of adverse events, which in some cases involved permanent disability (Kohn, Corrigan & Donaldson 2000). In addition to the measurable financial costs, there were other non-financial costs such as a loss of trust in the health care system and decreased patient satisfaction with care, and societal costs associated with people being unable to contribute to society while recovering from these adverse events (Kohn, Corrigan & Donaldson 2000).

The report aimed to break the cycle of inaction on adverse events in hospitals by making the point that patient safety required a comprehensive approach in order to reduce the number of adverse events with an emphasis on designing safety into the system. Four key recommendations identified the following components of the comprehensive approach to patient safety:

- leadership and knowledge,
- identifying and learning from errors,
- setting performance standards and,
- expectations for safety; implementing safety systems in health care organisations (Kohn, Corrigan & Donaldson 2000).

Following on from the IOM report, the global need for patient safety and quality of care was first discussed at the 55th World Health Assembly in 2002 (WHO 2017). Since 2002, policy-makers in many countries have become aware of the initiatives developed to improve the care and safety for

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[14] 44,000 deaths in Colorado and Utah with 98,000 deaths in New York. Deaths related to motor vehicle accidents (43,458), breast cancer (42, 297) or AIDS (16,516) (Kohn, Corrigan & Donaldson 2000; WHO 2010).

patients (WHO 2017). The World Health Organization (WHO) Patient safety program was launched in 2004 with the goal for all being: ‘First do no harm’ to patients (WHO 2010). Overall the Patient safety program aimed to achieve a trustworthy system of health care delivery. The participants in the study found they were at risk of harm from the health professionals in hospital and that influenced their capacity to trust the health professionals to deliver safe care.

Further to these developments above, a number of organisations developed their own definitions of patient safety. The Australian Commission of Safety and Quality in Health Care (ACSQHC) defined safety as ‘reducing the risk of unnecessary harm associated with healthcare to an acceptable minimum’ (ACSQHC 2017). Similarly, the WHO (2019) defined patient safety as ‘the absence of preventable harm to a patient during the process of health care and reduction of risk of unnecessary harm associated with health care to an acceptable minimum’.

Emmanuel et al (2008) described the goal of patient safety is to minimise adverse events along with eliminating preventable harm. The participants in the current study suggested they were the ones actively seeking to minimise adverse events and reducing preventable harm through their T1D self-management and did not feel health professionals had the same focus. Unfortunately, the WHO (2017) stated that globally there have been limited systemic improvements for patient safety in health care over the last 15 years and this lack of systemic improvement may be a contributing factor for the experience of the participants in the study towards feeling unsafe in hospital.

However, despite all these definitions of patient safety from an Australian and International perspective, the Australian Institute of Health and Welfare (AIHW) recognised that there is limited national data available on patients’ experience of safety in hospital (AIHW 2018a). The study has therefore added to the body of knowledge concerned with the patients’ experience of safety in hospital. The new knowledge was achieved through the development of a theory about the experiences of the participants with T1D while in hospital. At the core of these experiences is the participants’ need to keep themselves safe, despite the existence of policies geared toward patient safety while in hospital. The participants in the study acted to keep themselves safe from preventable harm, which, the Commission identified as one of their key aims directed towards health systems and health professionals (AIHW 2018a). As well as keeping themselves safe from harm, these participants were aware of the need to maintain control of their T1D while in hospital in order to reduce their risk of infection and increased length of stay[15].

8.4.2 Patient involvement in their own safety

The experiences of the participants in the study showed that they adapted to the role of guarding their own safety. Their adaptation was largely a result of feeling their T1D would not be well managed by health professionals in hospital, leaving them at risk of preventable harm. Furthermore, participants experienced limited opportunities to discuss their T1D management in hospital with health professionals to involve the participants in discussing leaving participants with the responsibility of self-managing. The participants' decision to be involved in their T1D self-management was in response to their need to maintain their safety in hospital.

Following on from the focus on improving patient safety in healthcare, there has been an increased interest on the level of patient involvement in maintaining their own safety (Schwappach 2010; Rathert, Huddleston & Pak 2011). Entwistle (2007) and Sahlstrom, Partanen and Turunene (2014) suggested involving patients in the promotion of safer care, along with supporting them to be responsible for their own safety in hospital. Bishop et al (2015) suggested involving the patient in recognising risks and consequently preventing harm, is a key strategy for improving patient safety in hospital. This key strategy has evolved from the recognition that the patient needs to be an integral part of the care team (Bishop et al 2015). Some examples of patient involvement in their own safety include activities such as verifying that the health professionals have washed their hands, marking surgical limbs pre-operatively and medication safety (Rathert, Huddleston & Pak 2011). Importantly the patient is recognised as being at the centre of fragmented health care as often there are a variety of health professionals involved in the provision of care and they may not communicate with each other. Therefore, Schwappach (2010) suggests patients should be routinely involved in patient safety in the same way as they are involved in other components of their care.

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[15] Reduced risk of infection and reduced length of stay are also aims of the Commission (AIHW 2018a).

Sutton, Eborall and Martin (2015) suggested that there is some debate about the level of involvement patients should have in maintaining their own safety in hospital. The arguments against involving patients in their own safety include concerns about:

- the increased level of vigilance imposed on patients
- the level of willingness of patients to speak up if they feel unsafe
- a shift of responsibility to patients may erode trust in the relationship between patient and health professional
- a reduction in the vigilance of health professionals
- health professionals feeling threatened by patients who challenge them in situations in which the patient feels at risk (Sutton, Eborall & Martin 2015).

The current study found that participants relied heavily on their own vigilance and had the capacity and willingness to assert their expertise to keep safe. Participants had already experienced trust issues in hospital due to their concerns about the health professionals' lack of knowledge and expertise in relation to T1D. Further, participants had experienced a lack of acknowledgment by health professionals of the participants' own expertise in managing their T1D. Hence, the experiences of the participants in this study counter the main concerns raised by Sutton, Eborall and Martin (2015) because they were actively being vigilant and involved in maintaining their safety in hospital.

Sutton, Eborall and Martin (2015) also provided arguments for patient involvement in their own safety in hospital. They stated the recognised benefits for patients being involved include assisting in treatment selection, managing chronic conditions safely, and being aware of safe medication management and infection reduction (Sutton, Eborall & Martin 2015). The criteria enabling patients to be involved in their own safety include: the recognition of the patient's expertise in their own conditions, a high level of motivation for a good outcome and the ability to monitor any misinformation or poor care received and then take action (Sutton, Eborall & Martin 2015). In the current study the participants with T1D demonstrated that they had the capacity to be involved in their own safety based on the afore-mentioned criteria.

In 2017 the WHO's Patient for Patient safety program indicated the need for more active patient involvement to assist in the prevention of health care related risks (WHO 2017; Pomey et al 2018).Three areas identified by WHO (2017) as key contributors to the quality of the care patients received are:

- patients being knowledgeable about their own historical health background,
- the patient's own interest and motivation for positive health outcomes and
- the patient's ability to be able to recognise and then communicate changes in their signs and symptoms of illness.

The participants in the study were able to meet all three of these key contributors to quality care by being experts in their own T1D, through being motivated to remain well and by recognising their own body's responses to illness. Therefore, the participants in the study were actively contributing to their own quality care when it came to their T1D management in hospital. While they were capable of contributing to their own quality care in hospital, they still required health professionals to acknowledge their expertise, rather than provide unwarranted judgements. Furthermore, participants actively contributed because they believed the health professionals were not able to provide quality care, which left the participants feeling unsafe.

8.4.3 Making hospital safe for people with diabetes

The substantive grounded theory generated in the study shares some commonalities with The *Making hospitals safe for people with diabetes* report by Diabetes UK (Watts & Rayman 2018). The report acknowledged people with diabetes are essentially not safe when admitted to hospital (Watts & Rayman 2018). The report focuses on what health professionals can do to ensure the hospital environment is safer for patients with diabetes (Watts & Rayman 2018). The intent of the report was to achieve the following goals:

- 'People with diabetes knowing what care to expect in hospital and feeling able to ask for it', and
- 'People being able to self-manage their diabetes where appropriate and having access to the right food at the right time during their stay' (Watts & Rayman 2018, p. 15).

The experiences of participants in the study indicated that these goals are currently not being achieved in an Australian context. The participants were provided with limited opportunities to discuss their diabetes management with health professionals, and as a consequence, they mostly self-managed by default. While access to food at times was problematic it was not an overall major focus of those in the study. Overall, the experiences of the participants in the study showed that they had to keep themselves safe while in hospital because there was limited attention given to the management of their T1D by health professionals. The study differs from the Diabetes UK report as it provides a unique perspective of the self-management experiences of the participants with T1DM in hospital. In this way, the study offers an original contribution to knowledge through generating the substantive theory of *Keeping Self Safe*.

The NHS digital (2018) *National Diabetes Inpatient Audit (NaDIA) 2017: Patient experience survey* also provides information from the perspective of patients with diabetes' while in hospital. Limitations of the audit are that it is a quantitative satisfaction survey with data providing only a snapshot because it is only collected on two allocated days. In addition, the survey did not distinguish between types of diabetes, which is a key consideration because there are significant differences in the experiences and management of people with T1D and type 2 diabetes (T2D). The current study, has, therefore added new knowledge to address these limitations by focusing on the qualitative perspective of the experience of T1D management in hospital.

8.5 The Social Construction of Keeping Self Safe

Social construction is how people perceive and experience their social world and, based on these perceptions and experiences, people construct meaning in their lives. By using a social constructionist perspective, I was able to interpret the experiences the participants with T1D had in relation to their self-management in hospital. The participants in the study based the construction of their experience of T1D self-management in hospital on the experiences they had when interacting with health professionals in hospital and the subsequent perceptions they developed from these interactions. Most of the participants had previous negative constructions about their interactions with health professionals in hospital, which certainly shaped their construction of their most recent experiences of T1D self-management in hospital. As a result of these interactions the participants relied on their everyday construction of T1D self-management in hospital. They interpreted their experiences in hospital to be inadequate in relation to their T1D management and this led them to being adamant that they would continue their T1D self-management in hospital in order to remain safe.

While physiological safety was important for remaining well, emotional safety of the participants was also important. Participants experienced a range of emotional responses to their interactions, or lack of interactions, with health professionals. Some participants felt they were not listened to in relation to their lived experience of their T1D and their expertise was not being acknowledged. Not being listened to led participants to feel ignored and having their expertise being devalued led participants to feeling frustrated with health professionals. In addition, constantly being vigilant about the potential of being harmed left participants feeling stressed about their wellbeing and safety in hospital. Overall, the participants believed health professionals did not view their T1D management as important, which further exacerbated their feeling of being unsafe in hospital. These negative constructions led the participants to feel anxious about future episodes of hospitalisation.

These emotional responses can be viewed as a form of diabetes distress because the participants were subjected to diabetes-related stigma as well as constantly dealing with health professionals' lack of understanding of living with and managing T1D (Hendrieckx et al 2016). Diabetes distress, as well as being under stress from being in hospital, can influence self-management, especially its healthy coping component (Hendrieckx et al 2016). Lack of acknowledgement by health professionals of the participants T1D needs and preferences is failing to provide a level of emotional support through not providing holistic care (Adamson et al 2012). Lack of emotional support leaves patients unsatisfied with their care (Adamson et al 2012) and for the participants in the study reinforced the belief that they were unsafe in hospital.

Within the hospital there is a dynamic interplay of competing perspectives and this was an evident aspect in the current study. The usual societal construction of the hospital is hierarchal in nature with health professionals viewed as the experts and the patient role traditionally being viewed as the passive recipient of care. In addition, hospitals are focused on cure rather than the management of chronic conditions, which means that the focus of care is on acute conditions. However, for the participants in the study, a number of these traditional constructs were challenged in the study. For example these participants were often in a position of having to reject the traditional health professional-patient relationship. Moreover, they often challenged the constructs of expert knowledge, had their trust in health professionals eroded and had to become agents in their own care. Their construction of *Keeping Self Safe* by remaining actively engaged in their T1D self-management challenged the usual assumptions about being a patient in hospital who would normally have trust in and accept the care of the health professional. Furthermore, due to the participants views of limited health professionals knowledge about T1D, the participants felt they could not rely on the health professionals' expertise keep them safe from harm.

Keeping Self Safe was constructed by the participants in response to their interactions with health professionals and led them to question the level of knowledge and competence of the health professionals. Assessing interactions with health professionals against their own priorities, preferences, beliefs and views of T1D self-management led participants to determine a reasoned course of action based on their own experiential knowledge and previous experiences. Courses of action were also as a result of their knowledge and understanding of the consequences of mismanagement of their T1D, thus driving them to protect themselves through reliance on their everyday self-management to keep safe and well in hospital.

8.5.1 Influence of knowledge on safety

The meanings participants attributed to their T1D self-management experience in hospital were shaped through their interactions with health professionals, and these meanings influenced the participants' actions (Blumer 1969). Overall the participants determined that health professionals did not have a good knowledge or understanding of T1D and this assumption stemmed from their interactions with the health professionals they came into contact with in hospital. Participants interpreted health professionals' limited knowledge of T1D, through the actions of the health professionals. These actions included being met with blank stares or being confronted by health professionals' unsubstantiated judgements on the participants' capacity to self-manage their T1D. Pomey et al (2015) suggested that people with chronic conditions adopt practices in hospital in order to compensate for and adapt to their perceived inferior health care. The interactions with health professionals shaped the participants' actions to continue self-managing to ensure that health professionals could not potentially cause them harm through T1D mismanagement. Participants conveyed their meanings through their actions of continuing their T1D self-management and by being vigilant and asserting their expertise to protect themselves from being harmed by health professionals.

People living with T1D acquire experiential knowledge of their condition through the process of continuous learning (Paterson & Thorne 2000; Pomey et al 2015). Continuous learning enables people with T1D to understand their own individualised symptoms of their condition and how different management strategies for such symptoms work for them. The study shows that each participant experienced aspects of their T1D differently, and as a result their management is individualised in their responses to their condition. Through the process of becoming the expert in their body's response to their T1D, they also develop an unwavering trust in themselves as being capable and competent self-managers.

Furthermore, there was an evaluation by the participants in the study of how health care was received. Their evaluation of the quality of the care received was achieved through comparison of how the care aligned with their personal preferences of T1D management (Pomey et al 2015). These personal preferences of care can be linked to the individualised context of managing T1D and also the need to maintain control over their T1D. Participants felt overall there was a lack of consideration of their personal preferences due to the perception that health professional did not understand or acknowledge the individual nature of T1D.

The participants in the study also showed an in-depth understanding of the technology they used to assist them to manage their T1D. The technology included continuous glucose monitoring (CGM) and insulin pumps. One participant, Dave, had even developed his own App to support him to manage his T1D. Dave's example shows a high level of engagement in and understanding of

T1D management. All the participants were proactive in continually learning about managing their T1D. Their in-depth knowledge of their bodies and their body's response to their condition and other factors enables people living with T1D to keep themselves safe every day. The participants' in-depth knowledge was relied on in hospital and used to counteract the fear of harm they experienced when they perceived they were at risk if the health professionals were to manage their T1D.

Participants in the study assessed the 'scientific knowledge and technical know-how' (Pomey et al 2015, p. 1) of the health professionals they encountered in hospital and compared it to their own experiential knowledge. One example was insulin pump management and CGM use in hospital. Health professionals deemed participants capable of using this technology in hospital without any form of assessment. This set of actions caused the participants to recognise that the health professionals did not have the required understanding of the technology they were using to self-manage. For example, participants were left to manage their insulin delivery via their insulin pump at the insistence of the health professionals. In this scenario, participants interpreted the health professional as being fearful of the technology because they lacked knowledge about how the insulin pump worked. Overall, the participants' assessment of the health professionals' knowledge and technical know-how suggested to them that the health professionals were not capable of safely managing T1D on their behalf.

The recognition of the health professionals being the expert was therefore challenged by the experiences of the participants in the study. According to Pomey et al (2015), patients with chronic conditions are known to take charge of certain health care activities to mitigate the recognised deficiencies of health professionals. Sometimes people take charge of their health care with the health professionals being aware but on other occasions the health professionals are unaware or the person takes action in contradiction to the advice of the health professionals (Pomey et al 2015).

The participants relied on their T1D expertise to continue their self-management in hospital to keep themselves safe from harm. In addition, relying on their expertise enabled them to maintain control of their T1D, which they had worked so hard to maintain out of hospital. Participants therefore asserted their expertise and knowledge to prevent mismanagement of their T1D occurring in hospital based on their priorities and preferences for management.

8.5.2 Influence of trust on safety

The construct of the health professionals being trustworthy was also challenged in the study because the participants experienced issues of trust with health professionals in hospital. These issues with trust stemmed from participants’ previous unsatisfactory hospital experiences and led them to construct their expectations of their current hospitalisation. Due to the lack of trust, participants wanted to, or felt they had to, continue their T1D self-management to remain safe. Even if participants did have a level of trust in health professionals, they would possibly want to remain in control of their self-management, but this would be by choice rather than necessity.

The lack of trust participants had in health professionals was also related to their perception that health professionals had a lack of knowledge of T1D. This perceived knowledge deficit meant participants’ limited their reliance on health professionals to keep them safe. Participants limiting their reliance on health professionals further decreased their capacity to develop trust in them.

Participants in the study had the confidence and trust in themselves to take action by speaking up when they identified that health professionals’ actions (treatment plans) could potentially affect their T1D control. The participants asserted their expertise through their reliance on their experiential knowledge of their T1D and their ability to communicate with the health professionals, rather than viewing the health professionals as the dominant decision maker.

Participants were not undertaking these actions to be disrespectful of the health professionals, but they needed to assert themselves in order to prevent harm being caused to them through instability of their T1D. People who live with a chronic condition experience a continuously changing perspective of their condition, which enables people ‘to make sense of their experience’ (Paterson 2001, p. 23). Paterson (2001) suggested health professionals do not have this level of experience or perspective so they lack the ability to make sense of someone else’s T1D especially when it does not follow their understanding about the condition. Essentially, the contextual decision making behind self-management is invisible to anyone other than the person with T1D, which could contribute to the misunderstanding of the complex nature of T1D.

8.5.3 Influence of communication on safety

Limited discussions initiated by health professionals about T1D management reinforced participants interpreted health professionals' knowledge deficit. Poor communication about T1D management in hospital therefore led to the interpretation of being unsafe. The participants self-managed by default as there was limited discussion about how their T1D would be managed in hospital. Therefore, the participants relied on their everyday self-management construction to keep safe. They adopted an active role in their care in hospital despite the limited health professionals' support to avoid experiencing symptoms associated with their T1D. To keep safe in hospital they took the initiative to engage in practices that enhanced their T1D management whether or not there was any discussion or interaction from the health professionals.

The ACSQHC identified that patient/clinician communication is a key component of patient safety in the hospital (ACSQHC 2016a). Iedema and Manidis (2013) recognised that the rising complexity of care and the increase of people with chronic conditions place additional demands on the communication requirements of health professionals. However, that being said, poor communication is known to increase the risk of errors in healthcare; therefore effective communication is essential to the provision of quality and safe care (Iedema & Manidis 2013). In order to feel safe, patients need access to open, timely and accurate communication with health professionals about their health care in hospital.

Ringdal et al (2017) found that when patients were able to express their feelings and thoughts to health professionals in hospital, they felt understood. Furthermore, being able to express themselves led to patients feeling safer and included as active participants of the health care team. Being able to participate in their care generated a sense of interest in the patient, which in turn assisted the patient to feel safe (Ringdal et al 2017). On the other hand, feeling ignored led participants to believe that health professionals were not interested in how they felt or what they knew, which could result in feeling unsafe. Participants in the current study experienced negative interactions, which led them to feel unsafe and pushed them towards managing their own T1D in order to feel safe, even when the effects of being in hospital impacted on self-management.

8.5.4 Engaging in patient safety

The focus of patient safety is on the prevention of errors and adverse events associated with being a recipient of health care. On the other hand, *Keeping Self Safe* focuses on the person preventing harm being caused to them by health professionals by choosing to self-manage their T1D in hospital. The choice to continue self-managing is based on their everyday construction of self-management. Davis et al (2007) suggested that patients should not feel they will receive substandard care if they are unable to contribute to their own safety, which was certainly a concern expressed by the participants in this study. This concern meant that participants were under pressure to maintain their own safety even when they did not have the capacity to do so due to acute illness and surgery.

While it is recognised that engaging patients in patient safety initiatives can possibly prevent incidents from occurring in hospital (Vaismoradi, Jordan & Kangasniemi 2015) participants in the current study were not engaged by health professionals to keep themselves safe specific to the management of T1D. Instead, the participants actively engaged themselves in their T1D self-management in hospital to keep safe for a number of reasons. First, they perceived and experienced health professionals as having a knowledge deficit about T1D self-management. Second, they had a lack of trust in health professionals' abilities to correctly manage their T1D. Third, they often felt they were being negatively judged by health professionals. Negative judgement was viewed by the participants as unwarranted because health professionals had not actively engaged in discussion around T1D self-management with the participants. Fourth, they experienced limited opportunities to discuss their preferences for their T1D management with health professionals. Finally, and most importantly, the participants believed that the health professionals did not understand how the person's T1D needed to be considered as an integral part of the holistic management of the person while in hospital. These participants were willing and able, as much as their circumstance allowed, to participate in their care to prevent errors from occurring around their T1D management.

All the participants in the study had significant knowledge of their T1D, through numerous years of self-management experience along with their own beliefs on how they preferred to self-manage. Vaismoradi, Jordan and Kangasniemi (2015) suggested that patients' knowledge, beliefs and their experiences influence their decisions to engage in patient safety. Furthermore, Vaismoradi, Jordan & Kangasniemi (2015) indicated that patients do have a significant role to play to enhance their safety in hospital based on the knowledge, beliefs and experience.

Ultimately patients should feel safe in hospital however, it was not the experience for the participants in the study. They took on the role of maintaining their own safety in hospital based on the lack of patient centredness and the lack of acknowledgement they experienced specific to their T1D self-management. The unique perspective of the participants' experience of patient safety suggests despite policies being in place they may not be enacted in practice and are not necessarily allowing patients to feel they are safe in hospital.

8.5.1 Links to existing theories

There are two existing theories that may offer some explanations for the protective actions participants took when *Keeping Self Safe*. These theories are the Protection Motivation Theory (PMT) and the Health Behaviour Model (HBM). The PMT was initially developed in 1975 with fear being identified as an underlying motivator to protect oneself against danger or to motivate oneself to move away from harm (Rogers 1975). PMT explains how individuals cope with and make decisions using a threat appraisal process (perceived or identified; hospital influences) and a coping appraisal process (efficacy and self-efficacy; everyday influences) during harmful or stressful events (Rogers 1975; Floyd, Prentice-Dunn & Rogers 2000).

The participants in this study expressed that they anticipated negative consequences in hospital if they were not in the position to maintain control of their T1D and if health professionals were controlling their T1D (*perceived threat*). Hence, they had a strong desire to continue to self-manage by relying on their everyday self-management expertise in order to avoid the potential negative consequences of hyperglycaemia or hypoglycaemia (*efficacy*). As the participants were actively engaged in their self-management, they believed they had the capacity and ability to maintain control of their T1D because they were motivated to protect themselves from harm (*self-efficacy*). While some participants acknowledged that they did not always get everything right with their T1D self-management, they were more willing to tolerate the potential risk they could cause to themselves as opposed to the risks they felt the health professionals would subject them to if they managed the T1D on the patient's behalf.

Previous admissions to hospital enabled the participants to identify the threats that existed in hospital in relation to their T1D (*identified threat*). Consequently, they had developed a number of coping strategies to mitigate such threats. For example, participants experiencing insulin being confiscated from them by health professionals when they were admitted to hospital. Their experience led the participants to develop the strategy of hiding insulin they had in their possession so they could still access their medication when it was required. Through having access to self-management equipment, enabled the participants to feel safer in hospital. Therefore, the 'protection motivation arises from the cognitive appraisal of a depicted event as noxious and likely to occur, along with the belief that a recommended coping response can effectively prevent the occurrence of the aversive event' (Rogers 1975, p. 99). Protection Motivation Theory may therefore explain the internal drivers behind the theory of *Keeping Self Safe*.

It has been suggested that PMT contains some similarities to the Health Belief Model (HBM), considering both theories describe health protective behaviours that arise from the need to protect oneself from a perceived threat in order to avoid negative outcomes (Floyd, Prentice-Dunn & Rogers 2000). The HBM 'relates psychological theories of decision-making (which attempt to explain action in a choice situation) to an individual's decision about alternative health behaviours' (Maiman & Becker 1974). According to Bishop et al (2015, p. 3020) 'the HBM provides an opportunity to explore how health-care provider behaviour can influence patient perceptions of patient safety and the likelihood of patient involvement in patient safety behaviours'. The HBM contains six constructs within the model, which are:

1. Perceived susceptibility
2. Perceived severity

3. Perceived benefits
4. Perceived barriers
5. Cues to actions
6. Self-efficacy (Rosenstock 1974; Bishop et al 2015, p. 3021).

There is a *perceived susceptibility* as to whether individuals regard themselves as being at risk of harm due to engaging or not engaging in a particular behaviour. The participants in the study perceived they would be harmed in hospital by health professionals, so they engaged in self-management behaviours and used their contextual decision making to keep themselves safe. By not performing the health behaviour of self-management of their T1D, they perceived there could be serious harm caused to them by health professionals (*perceived severity*). The *perceived threat* is constructed by the individual's interpretation of *perceived severity* and the *perceived susceptibility*, which leads to an action being undertaken. In the study, the participants perceived that the threats to their T1D management were the *hospital influences* and they took action knowing that the consequences of not self-managing their T1D were acute complications or could be death.

The *cue to action* for the participants was to reduce their risk of illness by keeping their BGLs in their target range and they did this by relying on their *everyday influences* and maintaining the self-management of their T1D. According to Vaismoradi, Jordan & Kangasniemi (2015) patients' abilities and health beliefs should be accommodated in health care systems to ensure patient safety. The HBM may therefore also provide some understanding of the actions of the participants with T1D in relation to the actions they took to keep themselves safe in hospital through their self-management.

Participants in the study believed they were making the best contextual decisions possible while in hospital to keep themselves safe. They stayed true to their internal protective motivation to keep safe through reliance on their *everyday influences on T1D self-management* to prevent harm being caused to them by health professionals in response to the *hospital influences on T1D self-management.*

8.6 Chapter summary

Chapter eight presented the substantive grounded theory, which provides an interpretation and explanation of T1D self-management in hospital. *Keeping Self Safe* was the social construction participants with T1D experienced as a result of their interactions with health professionals in hospital and their interpretation of these interactions. *Keeping Self Safe* was influenced by the participants' priorities and preferences for their T1D self-management, which they had constructed through their years of lived contextual experience (*everyday influences*). In addition, their previous hospital admissions and their expectations of the health professionals in hospital influenced their need to keep safe (*hospital influences*). Overall, these influences reflected the multiple realties of the participants' experiences of T1D self-management in this study.

The substantive grounded theory generated by the study offers an insight into the individual's experience of T1D self-management in hospital, differing from the intent of current Australian and International policies that focus on the safety of patients in hospital. While policies for patient safety are in place, this study shows that these policies are not always actualised in the everyday practices of health professionals in the hospital. Participants were shown to be doing their very best to keep safe in hospital because they did not believe that the health professionals they encountered had the capacity to keep them safe.

The in-depth participant descriptions of their experiences of T1D self-management while in hospital can offer many useful understandings of the consumer perspective. The consumer perspective needs to be recognised by health care systems and health professionals in order to improve the care provided and to increase the feeling of being safe for people with T1D in hospital. These insights provide new knowledge about the experience of people with T1D in hospital who participated in the study, which has important implications for future practice, education, research and policy around diabetes self-management in hospital. The following chapter will discuss the recommendations from this study along with the study's strengths and limitations and concluding thoughts.

Chapter Nine: Conclusion

9.1 Chapter overview

Chapter eight presented the substantive grounded theory of the experience of type 1 diabetes (T1D) self-management in hospital: *The Social Construction of Keeping Self Safe*. The overall theory explains the meaning of the experience of T1D self-management for the participants in the study and how both the *hospital* and *everyday influences* led them to take action in hospital. The theory provides a new understanding of self-management in hospital from the perspective of people living with T1D who participated in the study, which has not previously been explored. The chapter discussed the study's overall contribution to knowledge, along with the strengths and weaknesses of the study. In addition, the chapter will include the recommendations for practice, education and policy development along with suggestions for future research, which were developed from the findings of the study.

9.2 Contribution to knowledge

The study aimed to explore the experiences of T1D self-management in hospital, which had not previously been considered from the perspective of the person with T1D. From the literature reviewed in Chapter two (see page 14) it was evident that there were numerous studies demonstrating health professionals have a limited knowledge of managing diabetes in hospital and a recognised need for additional diabetes education. Furthermore, the focus of the existing literature has been on health professionals' management of diabetes in hospital. None of these reviewed studies identified that health professionals could learn from people living with T1D about the condition and its management. This limitation existed despite there being evidence of the development of self-management expertise for the person living with T1D. Although some examination of people's perspectives of diabetes management in hospital has been undertaken in the United Kingdom (UK), this exploration predominately relied on patient satisfaction surveys (Health and Social Care Information Centre (HSCIC) 2018). An in-depth insight into the self-management experience of people with T1D in hospital is lacking in the literature and there is no existing theory found that explicates the experiences of people with T1D while in hospital.

The aim of the study was achieved through adopting a constructivist grounded theory (CGT) method, which supported the development of a theory grounded in the participants' data. The theory of *Keeping Self Safe* suggests that participants with T1D in the study anticipated their diabetes would not be correctly managed in hospital due to a number of external factors (*hospital influences*). As a result, they chose to rely on their own self-management expertise (*everyday influences*) to keep themselves safe. Despite patient safety policies being in place for health professionals in hospitals, the participants in this study did not feel that the health professionals had the capacity to keep them safe in relation to their T1D management. This theory extends and contextualises a range of concepts, such as trust and being an expert, thereby providing an original contribution to knowledge. While some of the findings from this study align with the findings of previous research, this study is unique in that it focuses on the perspectives and priorities of the participants with T1D in hospital rather than those of the health professionals.

The views of consumers/patients are needed to improve health services by exploring and integrating their views into service delivery, such as the requirements for T1D self-management in hospital. Patients' views on safety, through their participation in their care, are important in improving health care delivery because they are the ones experiencing the care (Sahlstrom, Partanen & Turunen 2014). For the participants in the study, the care of their T1D in hospital was a result of their active efforts to remain engaged in their self-management rather than the results of a health care system that purports to support consumer-centred care and patient participation. As a consequence, it may be difficult for people with T1D to alter their perceptions of the care they will or will not receive in hospital. The participants in the study did everything they could to keep themselves safe, demonstrating that they had an overall lack of confidence in the health care system to not cause them harm.

9.3 Strengths of the study

The study applied the core tenets of CGT method to generate a substantive theory grounded in the experiences of the participants. The application of these core tenets suggest that the study has met the requirements of credibility, originality, resonance and usefulness (Charmaz 2014) (see 4.13 on page 73).

To my knowledge, this is the first study to explore the experience of T1D self-management in hospital and the first to construct a theory that explicates the experience of people with T1D keeping themselves safe. Through interviewing people with T1D, who had been to hospital and self-managed their diabetes, a rich insight into their experience is provided. The study provides the important health care consumers’ voice on their experience in hospital when admitted with a chronic condition, in addition to their primary admission diagnosis. The significance of the consumers’ perspective and their priorities has been generated from the data and has been shown to differ from the perspective and priorities of the health professional as highlighted in previous studies. In addition, some participants in this study were health professionals at the time they participated in this study that provides both an insider and outsider perspective of being a health care consumer with T1D in hospital.

Participants in the study were located across a number of states in Australia, in both metropolitan and regional areas, and were admitted to both public and private hospitals. As a result, of the varied geographical locations and hospital funding models, this study was able to explore a variety of T1D self-management experiences that were not solely influenced by public or private hospital or state based health care policies. In addition, four of the participants in the study were also health professionals, therefore offering a dual perspective. However, these four participants, despite being health professionals, still experienced the same issues as the non-health professional participants in terms of managing their T1D in hospital.

A publication of a peer reviewed article on the study (see Appendix 19 on page 282) along with acceptance of peer reviewed abstracts to present the study at National diabetes conferences (which were both awarded prizes) provide additional strength to this study. Regular monthly supervisor meetings throughout my candidature ensured strength in the study as I was consistently receiving feedback and were involved in discussions about the generation of my theory.

9.4 Limitations of the study

As with all research, there is a need to acknowledge the limitations of the study when considering the interpretation and application of the findings. Several limitations have been identified. The substantive grounded theory constructed in the study only provides an interpretation and understanding of T1D self-management in an Australian context. While there may be some similarities with experiences in other westernised health care settings, the results of the study may not be transferable to all hospital environments outside of Australia. However, when looking thorough the available literature no previously conducted research on this phenomenon was found. Therefore, the study may provide a starting point for health professionals who want to explore T1D self-management in hospital within their own health care system. Furthermore, the substantive grounded theory constructed from the study may bring about some understanding of the experiences of self-management in hospital for other chronic conditions that require individuals to self-manage every day to remain asymptomatic.

While the study was advertised Australia wide, only participants from South Australia, Victoria, New South Wales and Queensland volunteered their time to be involved in the study. Therefore, the states of Tasmania and Western Australia and the two territories, the Northern Territory and Australian Capital Territory, were not represented. The lack of Australia wide representation could be seen to be a limitation as some of the missing states and territories may have different health care policies, which may support self-management in hospital.

The gender and ethnicity of the participants in the study may be a limitation. Unequal gender distribution of the participants may influence the experiences represented. However, it is known that usually more females participate in research than males (Boughner 2012). As the study was not focusing on gender differences but on experiences of T1D self-management in hospital, the gender distribution did not have an effect on the substantive grounded theory generation. Most of the participants in this study were of an Anglo-Celtic Australian background. Their backgrounds mean that there was a limited opportunity to explore how differences in culture and ethnicity may also shape the experiences of people with T1D in hospital.

The study is not representative of all people living and coping every day with T1D. The sample size was small and the participants in the study wanted to remain actively engaged in their T1D self-management in hospital. On the other hand, some people with T1D may want to have a break, while being an inpatient, so may be happy to relinquish their self-management responsibility to health professionals. Therefore, the substantive grounded theory may not apply to all people living with T1D. However, the study was not an exhaustive attempt to generalise the experiences all people with T1D in hospital and it only provides an accurate portrayal of the experiences of those who participated in the study. That being said, my presentation of this study at a national diabetes conference in Australia (Australasian Diabetes Congress) led to social media posts and blogs that showed resonance with people living with T1D who did not participate in this study (Appendix 20 on page 291).

While the participants in the study were all actively engaged in their T1D self-management in hospital, it is recognised that this is not always possible due to illness and post-operative situations that may alter a person’s cognitive and physical capacity to self-manage in hospital. However, the study deliberately chose to exclude people who had been admitted to an Intensive Care Unit or for an issue directly related to their diabetes because the aim was not to include every person with T1D but those who experienced T1D self-management in hospital and those who did not have an admission diagnosis linked to their T1D.

All participants in the study had experienced admissions to hospital prior to their involvement in this study. Therefore, their construction of managing their T1D in hospital was shaped by previous hospital experiences and interactions with health professionals in hospital. A differing perspective may have been offered by a person living with T1D who had not been to hospital prior to being involved in this study because they would not have had previous experiences to shape their current experience.

The study only presents the interpretation of the recollected experience of people with T1D and does not offer any alternative perspective. The study does not acknowledge the experience of the interaction with people with T1D hospital from the health professional’s perspective. That being said, four participants in the study were health professionals at the time of participating in the study, so have had experience from both perspectives, but the current study focused on their experiences of being a patient with T1D.

Another limitation is the sole use of telephone interviews for data generation because the non-verbal cues are not seen by the researcher that would occur in a face to face interview. The use of phone interviews was based on the location of many of the participants being predominately interstate, or in regional South Australia. As suggested by Birks and Mills (2011) the potential for missing non-verbal cues in telephone interviews needs to be acknowledged. The only way to manage this potential limitation was to go back and listen to the audio recorded interviews. Additionally, each participant was followed up post interview to establish whether they were happy to be recontacted. All participants were agreeable to being contacted again if required.

Ward, Gott & Hoare (2015) suggested that phone interviews need not be viewed as the second best option to face to face interviewing in grounded theory research because people are phone savvy and there were some recognised benefits of not being interviewed face to face. These benefits included not feeling judged, feeling less inhibited and feeling less intimidated than if being interviewed face to face (Ward, Gott & Hoare 2015). These recognised benefits may enable participants interviewed over the phone to speak more freely than they possibly would in a face to face interview. All the participants in the study indicated that they felt comfortable being interviewed over the phone and that they felt able to convey all the information they wanted to impart during the interview, including the emotional impact of their experiences.

Despite the recognised limitations of the study, the purpose to construct a substantive theory and the aim to explore the experience of T1D self-management in hospital was met. As a result, new knowledge was generated that can contribute to recommendations based on the findings of the study.

9.5 Recommendations from the study

The substantive grounded theory of the study, *Keeping Self Safe*, contributes a new understanding of T1D self-management in hospital, which can lead to improvements in health care. While the study was undertaken in Australia, people all over the world are living with T1D. Hence, the generated theory has potential to be applied internationally especially in westernised countries with similar health care systems.

The in-depth descriptions of the participants' experiences of T1D self-management in hospital offer a number of insights into the consumer perspective. These consumer insights provide health professionals with knowledge of the specific challenges people with T1D experience while in hospital and the subsequent challenges for health professionals. The consumer voice in the study highlights the needs of the expert self-manager in hospital and challenges the prevailing social construction that health professionals are the experts and as being trustworthy. Furthermore, the idea that hospitals are safe-havens for patients was challenged in the study, because it was shown that participants with T1D felt unsafe in relation to their diabetes management and acted in order to keep themselves safe from harm (Ravenscroft 2010).

The following discussion includes recommendations from the study for clinical practice, education, policy development and future research. These recommendations have relevance for people living with T1D, health consumers, health professionals (including managers) and policy-makers.

9.5.1 Clinical practice recommendations

Flanagan et al (2018) recognised that people with diabetes have traditionally been prevented from self-managing their diabetes in hospital, and the consequences of this prevention have been far-reaching. The known consequences are general diabetes management errors and more specifically, insulin administration errors, meals being inappropriate with meal availability and timing being inappropriate, poor management of hypoglycaemia episodes and misuse of intravenous insulin infusions (Flanagan et al 2018). The variety of errors the person with diabetes in hospital is exposed to from the health professionals' management of diabetes leads to consequences for that person. These consequences include dissatisfaction with care, being disempowered by not being able to self-manage, increased length of stay in hospital and can unfortunately lead to serious harm and death (Flanagan et al 2018). In addition to the consequences for the person with diabetes in hospital (Flanagan et al 2018), the current study found participants did not feel safe unless they were self-managing their T1D in hospital. The following recommendations provide strategies for health professionals to improve support for the person with T1D in hospital.

9.5.1.1 Acknowledging expertise

People with T1D are known to become experts in their self-management and many remain highly motivated to ensure good outcomes for their diabetes while in hospital (Sutton, Eborall & Martin 2015). These people are well placed to monitor and act on any care that has the potential to cause them harm as a result of their expertise (Sutton, Eborall & Martin 2015). Health professionals need to recognise and acknowledge the experiential knowledge that patients' have as being a complementary contribution to health care in order to foster collaboration and to integrate patients into healthcare teams (Pomey et al 2015).

Acknowledgement and acceptance of the expert patient in hospital may require significant changes to the ingrained culture in healthcare to occur. Complex hierarchical social structures in exist in healthcare, and these structures impact on those patients within the hospital. The participants in the current study determined they were unsafe in relation to their diabetes management within the hospital system. They had gained this understanding through previous interactions within the complex social healthcare structures. The participants in this study identified themselves as the experts in their T1D management, but felt the health professionals did not see them that way, thus impacting on consumer-centred care and the safety of the person with T1D in hospital. Therefore, structural, organisational and cultural changes to overcome the ingrained hierarchy are needed so that there is an appreciation of the patients' expertise. For these changes to occur, the support of management and senior health professionals in hospitals is essential (Sutton, Eborall & Martin 2015). Pomey et al (2015, p. 17) stated:

> *'a deeper understanding of patient partnership should help build an improved healthcare system where patients experiential knowledge and unique position as experts living with the*

> *chronic illnesses allow them to be increasingly integrated and to have a greater role in ensuring optimal care'.*

Health professionals also need to recognise that the person with T1D and their expertise are a valuable resource in the management of T1D in hospital. Acknowledging and understanding the person's preferences and priorities for their T1D management in hospital can assist the health professional to provide appropriate support. Health professionals need to listen to the person living with T1D and acknowledge their extensive knowledge and experience from managing their diabetes 24 hours a day, seven days a week, 365 days of the year.

9.5.1.2 Acknowledging individual T1D requirements

In addition to acknowledging the expertise of people with T1D, health professionals need to recognise and accept the individualised nature of T1D. Participants in the study identified their self-management requirements and responses to self-management varied from person to person. Understanding each individual's T1D self-management preferences and priorities requires discussion about how the patient normally self-manages their condition at home and why they use certain self-management strategies. These discussions could occur at pre-admission appointments and during multiple points and interactions throughout the hospital stay. To adapt to each persons individualised context, a flexible and dynamic approach to care in hospital would be needed (Ortenblad, Meillier & Jonsson 2018). This type of approach would enable treatment regimens to be adapted to the everyday preferences and priorities of T1D self-management and the practical needs of the patient in order to be safe in hospital (Ortenblad, Meillier & Jonsson 2018). The actual needs of the patient are then seen to have as much importance as their admission diagnosis.

9.5.1.3 Acknowledging issues with patient-centred care

The participants challenged being judged as 'idiots' or as incapable when health professionals used dominating and dismissive attitudes. Such attitudes still exists in the current health care system despite recommendations for patient participation and patient-centred care (Longtin et al 2010). It is likely that these recommendations have not been instituted due to the focus on acute care in hospital, rather than on the ongoing management of a chronic condition with individualised needs. The current study shows that people with T1D have the capacity to provide and clarify pertinent information to health professionals about their chronic condition management. Through health professionals engaging and collaborating with patients with T1D, they can tailor care that meets the patients' preferences, which is a significant aspect of patient safety (Chaboyer & Tobiano 2015). True patient-centred care could help minimise some of the dilemmas people with T1D face in hospital in relation to feeling unsafe as the opportunity to develop collaborative plans of care would be available.

For patients to feel safe in hospital they require open, timely and accurate communication with health professionals about their health care. Castro et al suggested (2016, p. 1929) patient centredness is characterised by 'open communication of knowledge', which includes both the experiential knowledge of the person and the clinical knowledge of the health professional. There is a need for the open communication of knowledge in order for people with T1D to have improved experiences with health professionals in hospital. Open communication can lead both parties participating in discussions about what strategies will work best for the person with T1D. The participants in the study felt they were ignored or not consulted about their T1D management in hospital and this aspect of care needs substantial improvement. Snow, Humphrey & Sandall (2013, p. 7) stated:

> *'Doctors, nurses and others whose attitudes impact on patient care must be supported to extend that model of shared expertise to work with those with chronic illness, seeing the patient as part of the healthcare team, and the patient's condition-specific biomedical knowledge as a valuable resource, not a threat'.*

Senior leadership health professionals need to be supportive of practice implications to increase the likelihood that suggested changes will be implemented and resources dedicated to making changes based recommendations from the study's (Bombard et al 2018). In order to promote safe care for patients in hospital nurse leaders are required to support the cultural change to facilitate the valuing of patient participation by nurses (Sahlstrom et al 2018). Vaismoradi, Jordan and Kangasniemi (2015, p. 637) suggested the following practice recommendations relevant to the current study:

- 'Patient participation should be incorporated into health' professionals 'description of duties and the process and expectations of such collaborations should be outlined'
- Health care organisations should provide the necessary resources and infrastructures for patient participation and encourage healthcare team members' collaboration consistent with the mission of safer healthcare systems'.

9.5.1.4 Assessment of self-management

Participants in the study were not assessed by health professionals as to whether they had the knowledge or capacity to safely self-manage their T1D in hospital. In addition, health professionals did not attempt to ascertain the participants' attitude towards or their beliefs about their self-management. Vaismoradi, Jordan and Kangasniemi (2015) suggested that assessment of patients' knowledge, attitudes and beliefs should be undertaken in hospital in order to ensure patient safety. Furthermore, the patients' capacity to undertake T1D self-management and make informed decisions needs to be considered by health professionals rather than be unacknowledged or ignored. Entwistle and Watt (2006) identified there is a need to 'proactively approve' and support patients' knowledge and involvement in hospital. While this statement was founded in 2006, the participants in the current study experienced limited respect of or support in hospital for their vast knowledge of their T1D self-management and for their involvement in self-management. Health professionals who are not engaging in these conversations and assessments of people in hospital are subjecting the patient to being at risk of harm because they are not completely aware of what the patient is doing for example, insulin dose administered. By health professionals not being aware of their patients' self-management practices unintentional harm could be caused to the patients.

9.5.1.5 Adopting inpatient specialist teams

While these clinical practice recommendations could be implemented, another consideration is the need to develop inpatient specialist teams to support both people with T1D in hospital and the health professionals. The UK developed a report titled *Making hospitals safe for people with diabetes* that suggests some changes to the health systems' approach to care (Watts & Rayman 2018). Some recommendations from the report are relevant to the findings of this study include:

- all hospitals have multidisciplinary inpatient diabetes teams,
- the recruitment of health professionals who have specific knowledge about diabetes and
- better systems in place to provide the required support for hospitals (Watts & Rayman 2018).

These recommendations could be implemented in an Australian context to improve the experience and safety of people with T1D in hospital.

Additional recommendations from the study are to:

- develop systems in hospitals that identify people when they are admitted with T1D as a secondary admission diagnosis, which would allow for follow-up by health professionals with diabetes expertise.
- improve the pre-admission appointment for those with T1D. Improvements in these appointments would enable health professionals the opportunity to establish the person's usual self-management practices and preferences and to establish a collaborative plan of care.
- provide an estimation or actual amount of carbohydrate content contained in the meals being served to assist those people who are carbohydrate counting to make more informed decisions about insulin bolus dosages.

9.5.2 Education recommendations

The challenge for health professionals is to examine their practices, knowledge and skills when interacting with a person with T1D. Numerous studies concerning health professionals' knowledge of diabetes management demonstrate that health professionals do not have an adequate understanding of general diabetes management (see 2.7 on page 26). Most of these reviewed studies recommend health professionals need more education on diabetes and its management to improve their knowledge.

While, this recommendation is not new, studies continue to find knowledge deficits about diabetes management among health professionals. What is being missed in many of the studies, is the person's lived experience of T1D and their expert knowledge on their chronic condition. In addition, the way the health professionals can learn from the expertise of the person with T1D is missing. Furthermore, previous research has not acknowledged the individuality of people with T1D and the variety of tools people choose to use to manage their T1D.

In addition to providing further education to health professionals about T1D, education should be built on the premise that every person experiences and responds differently to their diabetes and its management. These differences are often the result of existing comorbidities. For example, they may have other autoimmune conditions such as coeliac disease to concurrently manage and that can lead to the person with T1D having to make alterations in their dietary intake to manage both conditions. Another example is gastroparesis, a known complication of T1D, which can slow gut emptying. An individual with this condition needs to take into consideration the timing of bolusing insulin for the carbohydrate content of a meal. Furthermore, different methods of insulin delivery, type of blood glucose monitoring (BGM) device used and the variations in responses to physical activity all lead to the need for individualised management of T1D. Health professionals need to acknowledge T1D self-management is more than a prescriptive regime and support the stance whereby the individual living with diabetes ‘is indeed the most reliable and accurate source of information about his or her physiological function’ (Thorne and Paterson 2001, p. 87; Visekruna, Edge & Keeping-Burke 2015).

While there is a focus on patient-centred care in current health professional education, such education is not preparing the health professionals for interactions with patients who have more biomedical and practical knowledge about managing of a chronic condition like T1D (Snow, Humphrey & Sandall 2013). This type of interaction between the expert patient and the non-expert health professional can lead to problematic interactions. When the non-expert health professional does not understand the expert patients’ self-management requirement or chooses not to trust the capabilities of the expert patient, then obstacles to improved health outcomes can appear (Snow, Humphrey & Sandall 2013). Therefore, health professional education needs to acknowledge the lived experience and expertise of those living with T1D.

Feijoo-Cid et al (2017, p. 2) suggested that health professionals need to shift their perception of patients and acknowledge the expert patient as ‘an endless source of learning’. The use of expert patients in discussing their illness narrative can provide undergraduate health professionals with an increased understanding of the individualised requirements, such as in those living with T1D, and to be more empathetic to the person living with a chronic condition (Spencer at el 2011; Feijoo-Cid et al 2017). One such method for this type of teaching is known as the Expert Patient Illness Narrative, which Charon (2007, p. 1265) suggested assists students to ‘recognise, absorb, metabolize, interpret and be moved by stories of illness’. Using stories of the experiences of people with T1D in hospital, such as of the participants in the current study, can be a powerful tool to educate health professionals and may lead to change in health professionals’ behaviour (WHO 2013).

Charmaz (2000) acknowledged the importance of illness narratives for those who are living with a chronic condition, such as T1D. These narratives can facilitate a better understanding of the many ways people with chronic conditions respond to living with their condition along with how they develop their own individualised responses to living with and managing their condition (Wellard 2010). For my study, the narratives of those with T1D show how they self-manage their condition in hospital and how they have constructed their experience, which may assist others with T1D going into hospital and improve management of those with T1D while in hospital. The opportunity to learn from the patient and to view them as the expert may require a cultural shift in the socially constructed hospital setting and the experience of illness. This kind of cultural shift would require the support of managers and senior health professionals.

A Diabetes Nurse Consultant in London, Ruth Miller, recognised the need for health professionals to possess core competencies to provide appropriate care for people with diabetes in hospital. As a result, Ruth developed the *Diabetes 10 point training* for health professionals in both the hospital and community settings in order to keep patients safe (Diabetes UK nd). Ruth and I have had preliminary discussions about how a program, similar to the one she developed, could be adapted and implemented into the Australian health care system. An implementation of this type of training would require evaluation for its effectiveness in improving knowledge and attitudes towards people with diabetes in hospital.

Health professionals should be educated about the need to provide encouragement and support to patients as required and they also need to be able to respect the collaboration with the patient about their T1D management in hospital (Vaismoradi, Jordan & Kangasniemi 2015). People with T1D want their self-management expertise recognised and validated by health professionals in hospitals, but in order for this to occur, there needs to be effective communication between the health professional and patient.

Health professionals need education on assessing the patients' capacity to self-manage in light of their health condition and their physical and psychological capabilities (Vaismoradi, Jordan & Kangasniemi 2015). There needs to be more effective communication with people with chronic conditions about how they would like to manage their conditions in hospital, hence providing the health professionals with the ideal opportunity to collaborate with the person about their plan of care and discuss the person's capacity to be involved in the plan and effectively self-manage tasks.

Hospital influences on T1D self-management need to be included in health professional education. The unjustified judgements directed towards participants in the study need to be recognised and considered by the health professionals because these judgements are often based on the health professionals' misunderstanding of the complexities of T1D self-management. Increasing the health professionals' knowledge and understanding about the preferences and priorities of the person living with T1D could help reduce diabetes-related stigma and the associated judgements of their self-management. Furthermore, an increase in health professionals' knowledge and understanding could lead to improved communication about T1D management in hospital, which could then lead to improved level of trust in health professionals by patients with T1D.

Professional development concerning technology use in self-management of T1D management is required, because participants in this study found health professionals were not familiar with pumps and continuous glucose monitoring (CGM). Therefore, participants were left to manage these technologies as a direct result of health professionals' limited knowledge. Expert diabetes health professionals could provide numerous in-service education sessions to increase knowledge on the function and use of various pumps, CGMs and *Freestyle Libre* Flash glucose monitoring,[16] which are all available and in use.

TID management technology has advanced from glucometers and insulin administration using a syringe and needle. While it is recognised that not all people with T1D in hospital will use some form of technology to manage their T1D, the uptake of pumps is on the rise; the National Diabetes Services Scheme (NDDS) data (from April 2010) suggested approximately 16% of all people with T1D over 18 years in Australia use a pump (W Campbell (NDSS) 2018, email, 4 October). In addition, the Australian Government provides subsidised funding for CGM in people with T1D under 21 years of age and negotiations are currently being undertaken to increase CGM availability to anyone with T1D who has a clinical need for this type of monitoring, for example those living with hypoglycaemia unawareness (Department of Health 2019). The increased use of technology increases the likelihood of these technologies being seen in hospitals.

There are also a number of people living with T1D who are developing their own do it yourself technology known as looping[17] to manage their condition. Diabetes Australia (2018) recently released a position statement about do it yourself (DIY) technology use to manage T1D, which non-diabetes and diabetes health professionals should be aware of. For health professionals, having access to knowledge about technology use in T1D management, would enable them to engage in discussions with people with T1D in hospital rather than ignoring the technology their patients use.

A number of the education strategies above need to be considered for embedding in undergraduate health professional education about patient participation in care, the expert patient and patient safety. A recent scoping exercise undertaken by the Australian Diabetes Educators

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[16] A *Freestyle Libre* Flash glucose monitoring device monitors interstitial fluid glucose levels via a sensor inserted under the skin. A device is used to scan the sensor which reads the BGL which appears on a reader device (Abbott Diabetes Care 2019).

[17] Looping is a do it yourself artificial pancreas system that uses an iPhone, an insulin pump and a communication device called a Rileylink which act together as an artificial pancreas (Diabetes Australia 2018)

Association (ADEA) found that variations exist in undergraduate nursing curriculums concerning diabetes and its management (Munt 2019). The findings of the scoping exercise led to the development of the National Diabetes Nursing Education Framework (NDNEF) project, which was funded by the National Diabetes Services Scheme (NDSS) that I am involved in as the Chair of the Expert Reference Group (Munt 2019). The NDNEF consists of diabetes specific competencies that nurses need to achieve in order to provide a high standard of diabetes care and provides support for further education and professional development in diabetes care and management for nurses (Munt 2019). The framework will be available from June 2020 for education providers of undergraduate nursing programs as well as for nurses working in a variety of practice settings.

It is also important to provide education to people living with T1D about how they can manage their diabetes in hospital. The findings of the study may be useful for organisations around Australia that provide advocacy support for people living with T1D. Education for national diabetes bodies about the consumers' experiences of managing their T1D in hospital could provide useful information for others living with T1D to prepare for going to hospital and to assist in keeping them safe.

9.5.3 Policy recommendations

9.5.3.1 Self-management policy

Currently, in Australia there is no national policy available to support people with T1D to self-manage in hospital. The development and implementation of such a policy could provide support for both people in hospital with T1D and the health professionals involved in their care. Currently in the UK they have a document titled *Self-management of diabetes in hospital document* by the Joint British Diabetes Societies for Inpatient Care Group (JBDSICG) (Flanagan & Watkinson 2012). The document supports the need to improve the care for the inpatient with diabetes (Flanagan & Watkinson 2012). The underlying principle of the document acknowledged that people with diabetes self-manage every day at home and should therefore be able to continue to self-manage in hospital (Flanagan & Watkinson 2012). Within the document is information on inclusion criteria for self-management of diabetes in hospital, exclusion criteria and the responsibilities of the health professionals (Flanagan & Watkinson 2012). The information contained in the document could be reviewed and adapted for the Australian health care context for policy development.

Another UK document that could have its content adapted into an Australian context for development of a self-management policy is *Making hospitals safe for people with diabetes* (Watts & Rayman 2018). This document contains a section highlighting the support needed for people to be able to self-manage their diabetes in hospital (Watts & Rayman 2018). One of the key recommendations within the document is the importance of hospitals having the correct systems and training in place for health professionals to support those who want to self-manage their diabetes in hospital (Watts & Rayman 2018).

Self-management in hospital guidelines aim to address the recognised gaps in quality and safety that people with diabetes experience during a hospital stay in the UK (Flanagan et al 2018). Flanagan et al (2018) suggested all hospitals in the UK implement a person-centred policy for self-management of diabetes. The underlying principle of the policy is the person with diabetes is responsible for deciding whether they will continue to self-manage in hospital. In addition to the self-management policy, written information would be included for health professionals explaining what their responsibilities are in relation to providing support and care for the person with diabetes (Flanagan et al 2018). Some of the suggested responsibilities for health professionals are:

- Provide the person with diabetes the opportunity to discuss their self-management, complete a self-management agreement form along with a written agreement around medication self -administration
- Involve the person with any decisions about their diabetes self-management and enable the person with diabetes to make the final decision
- Regularly assess the clinical condition of the person with diabetes to evaluate whether their clinical condition may impair their self-management ability
- Involve the hospital diabetes specialist team if there are doubts about an individual’s capacity to self-manage in hospital (Flanagan et al 2018)

Health professional responsibilities such as these would be required to provide support for successful implementation of a self-management policy in Australia.

9.5.3.2 Use of technology policy

A number of participants in the current study stated they were using CGM and pumps and recognised health professionals were not documenting BGLs or insulin administered at the bedside. The development of policies for the documentation of inpatient CGM and Flash glucose monitoring results is recommended. In addition, a policy for inpatients using pumps in hospital, along with development of a chart for documentation, is suggested. In Australia we currently have a National subcutaneous insulin chart for documenting insulin dosages. However, the chart does not have a section specific for pump use despite pumps administering insulin subcutaneously (ACSQHC 2019). Not only would the availability of such charts lead to accurate documentation for the provision of safer care, the existence of these charts would provide the opportunity for health professionals and people with T1D to engage in conversations about the technology used to manage their diabetes.

However, as with any policy, these recommendations require health professionals to embed them into their practice in order to facilitate improvement in health care. There are already a number of existing policies from the ACSQHC (2018) that focus on patient safety in hospital, in particular, consumer-centred care and patient participation in care. What the study found is that these existing policies are not always being implemented in practice. Therefore, the policy recommendations from the study would require evaluation following their implementation to ascertain whether they are being embedded in practice and whether the policies improve the support and care for and safety of people with T1D in hospital.

9.5.4 Future research

Future research generated from the findings of the study will provide additional insights into the experience of T1D self-management in hospital to further inform policy development and lead to improvements in clinical practice.

The following future research recommendations were developed during the production of the thesis.

- Examine in more detail the emotional and psychological impact that feeling unsafe in hospital has on people with T1D and whether it influences their capacity for self-management.
- Explore the influences of high patient turnover/shorter length of stay on the development of a trusting relationship between health professionals and patients with underlying chronic conditions.
- Explore health professionals' understanding of the complexities of everyday self-management.
- Determine health professionals' interpretation of the terms expert patient and what they believe the level of experiential knowledge of people with T1D is.
- Explore health professionals' acceptance of experiential knowledge and how it can be factored into developing collaborative plans of care for people with T1D.
- Explore the experiences and perspectives of health professionals who provide care to people with T1D in hospital, when T1D is not a primary admission diagnosis. This exploration would allow a more complete picture of T1D management in hospital to emerge.
- Undertake a Delphi study with health professionals, hospital administration and people with T1D, to build a new system for supporting people with T1D to be safe while in hospital with the aim being to improve current practice through co-design.
- Examine the constructed theory developed in this thesis to identify whether people living with other chronic conditions experience the need to keep themselves safe in hospital. This exploration could show transferability of the constructed theory of *Keeping Self Safe.*
- Explore the experiences of other groups of people living with T1D and their experience of self-management in hospital. For example, pregnant women with T1D and their experiences of self-management during labour, or children, adolescents and their family members' experiences of T1D self-management in hospital. In addition the perspective of people with T1D who identify as not being actively engaged in their T1D self-management could be explored.

9.7 Concluding comments

Every day people living with T1D are remaining well by carrying out numerous self-management tasks that rely on intricate and complex contextual decision-making and problem solving. Over time people living with T1D are known to become experts in their individualised self-management requirements as a result of their lived experience. On occasions people with T1D will be admitted to hospital for a range of admission diagnosis, yet despite their admission diagnoses, their T1D management needs to continue.

Currently in Australia we have no policy to support people with T1D to self-manage in hospital. Australia does, however, have in place a number of policies that aim to keep patients safe in hospital, to support patient-centred care and use shared decision-making. Yet the study found that people with T1D felt unsafe and unsupported in hospital and that from their perspective, health professionals are not acting in the best interests of patients because they do not follow the policies that support patient safety. As a result, the participants felt compelled to keep themselves safe through continuing their T1D self-management, being motivated by their internal driver to protect themselves from harm, because they cannot rely on being kept safe by the actions of health professionals in hospital.

People with T1D, who are in hospital, need to be able to collaborate with health professionals to enable them to make the choice to continue to self-manage, rather than being forced to self-manage, as the only option being available to them to keep safe. Patient participation in care is happening and people with T1D are actively participating in their diabetes management. However, consumer-centred care needs to be improved as a way of ensuring that people are safe in hospital and also to acknowledge the individualised needs of the person with T1D are being met. In order to provide safe and collaborative care for people with T1D in hospital, health professionals need to acknowledge the self-management expertise of these people and utilise this expertise when negotiating care.

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Appendix 1

Article search and selection

An initial search of relevant electronic databases focused on research published between 2005 and 2015 to ensure the retrieved studies were current. Articles were confined to those written in English as it is the researcher's first language and resources for translation were not available. The studies needed to be primary research specific to adults (18 years and older) who had experienced self-management of their T1D while admitted to hospital. The electronic databases initially searched were Cochrane database of Systematic Review, Scopus, Pubmed, and CINAHL. Keywords used were Type 1 Diabetes Mellitus, Type 1 Diabetes, Self-management or self-care, inpatient, hospital and adult.

The Cochrane database of Systematic Review had 16 reviews on Type 1 Diabetes but none of these reviews were found to be relevant to the review topic. There were 181 reviews for self-management which were screened and none were found to be relevant to self-management of T1D or self-management in the hospital setting.

The Scopus search used the key search terms Type 1 diabetes, self management or self care and inpatient. (TITLE-ABS-KEY (**diabetes** TYPE **1**) AND TITLE-ABS-KEY (**self-mangement** OR **self-care**) AND TITLE-ABS-KEY (**inpatient***)). This search retrieved 37 articles, the abstracts were reviewed and a number of studies were excluded as the studies involved people with T2DM, or focused specifically on children, or were related to the management of diabetes guidelines rather than research. Only one study met the criteria for further consideration and critique using this search method.

The Pubmed search used the key search terms Type 1 diabetes, self care or self- management and inpatient with the exclusion of Type 2 diabetes. (("diabetes mellitus, type 1"[MeSH Terms] OR "type 1 diabetes mellitus"[All Fields] OR "diabetes type 1"[All Fields]) AND ("self care"[MeSH Terms] OR ("self"[All Fields] AND "care"[All Fields]) OR "self care"[All Fields] OR ("self"[All Fields] AND "management"[All Fields]) OR "self management"[All Fields]) AND (inpatient[MeSH Terms] OR inpatient[All Fields])) NOT ("diabetes mellitus, type 2"[MeSH Terms] OR "diabetes type 2"[All Fields]). The above search retrieved 56 articles, the abstracts were reviewed and no studies were found to be relevant to the research.

The CINAHL database search used keywords Type 1 Diabetes, self-management and adults which retrieved 31 articles. All abstracts were read and the studies were screened for their relevance to the study. One study was found to be suitable for inclusion in this review.

The Diabetes Educator journal was manually searched using the terms Type 1 diabetes in all fields and hospital in all fields and self-management in all fields, from Jan 2005 through Jan 2015 in selected journals. A total of 114 articles were found and checked against the inclusion criteria and no articles were found to be relevant.

Manual search of reference lists of retrieved articles was performed along with reviewing of some relevant older studies and reviewing research which had cited these original studies.

Due to a lack of studies retrieved from the above searches the publication dates were increased from 2005 to 2015 to 2000 to 2015 in an attempt to include more literature relevant to the topic.

Appendix 2

Literature review Inclusion and exclusion criteria Table

Inclusion criteria	Exclusion criteria
Original primary research	Literature reviews; systematic or integrated
Published in English	Published in a language other than English
Participants of study 18 years or older	Participants of the study under the age of 18 years
Any methodology	Policies, opinion pieces, expert commentary
Hospital setting only	Community, Aged care or Primary health care setting
General ward environment admission	T1D admission in ICU TID admission as primary diagnosis Pregnant women in labour area Mental health facility
Some focus on T1D or broad diabetes management	Only focused on Type 2 diabetes

Appendix 3

Preliminary literature review thematic tables

Theme 1: *Management of T1D in hospital*

Theme	**Authors**
Self-management of T1D in hospital	Germain & Nemchik (1988)
Timing of inpatient diabetes management	Cohen et al (2007); Lampe et al (2014)
Inpatient hypoglycaemia management	Anthony (2007); Coats & Marshall (2013)
Glycaemic control with CSII use in hospital	Leonhardi et al (2008); Bailon et al (2009); Noschese et al (2009); Nassar et al (2010); Cook et al (2012)
Adverse events with CSII use in hospital	Noschese et al (2009); Nassar et al (2010); Cook et al (2012)
Health professionals and patients perspective towards inpatient CSII use	Cook et al (2007); Cook et al (2008); Noschese et al (2009)
Patient satisfaction of CSII use in hospital	Noschese et al (2009)
Health care providers' familiarity with CSII use in hospital	Cook et al (2007); Cook et al (2008)

Theme 2: ***Health professionals' knowledge of diabetes***

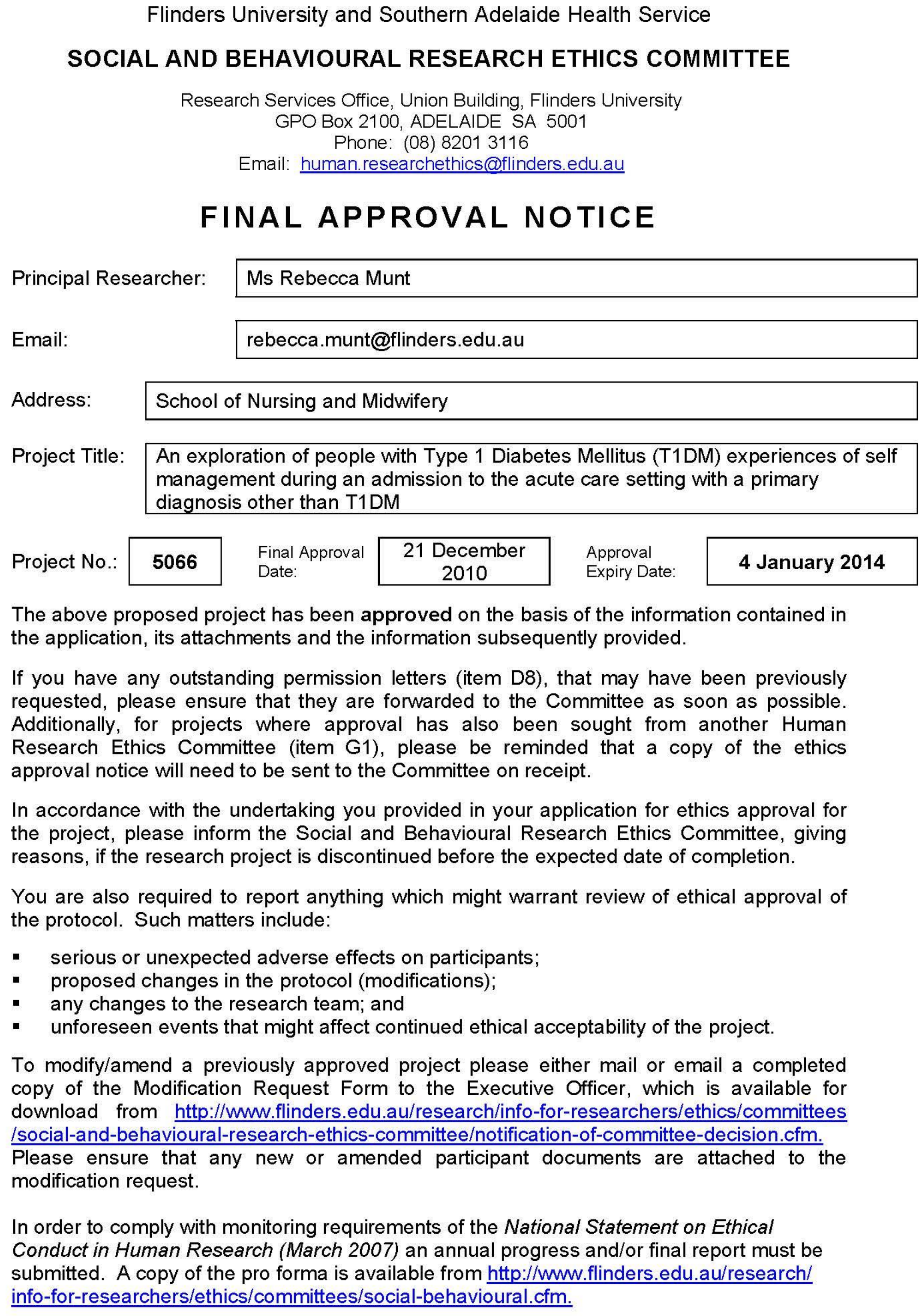
Theme	**Authors**
General diabetes knowledge	Gerard, Griffin & Fitzpatrick (2010); Trepp at al (2010); van Zyl & Rheeder (2008); Modic et al (2014)
Insulin knowledge	Cook et al (2007); Gerard, Griffin & Fitzpatrick (2010); Ahmed et al (2012); Lee et al (2013); Modic et al (2014); Yacoub et al (2014)
Dietary requirements	Gerard, Griffin & Fitzpatrick (2010); Park et al (2011); Oyetunde & Famakinwa (2014); Yacoub et al (2014)
Blood glucose monitoring	Cook et al (2007); Yacoub et al (2014)

Theme 3: ***The expert patient***

Theme	**Authors**
Health professionals exert their expertise	Thorne, Ternulf Nyhlin & Paterson (2000); Wilson, Kendall and Brooks (2006)
Nurse response to the expert patient	Wilson, Kendall and Brooks (2006)
Recognising power imbalances	Paterson (2001); Henderson (2003); Wilson, Kendall and Brooks (2006)

Appendix 4

Ethics final approval notice



Flinders University and Southern Adelaide Health Service

SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE

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FINAL APPROVAL NOTICE

Principal Researcher: Ms Rebecca Munt

Email: rebecca.munt@flinders.edu.au

Address: School of Nursing and Midwifery

Project Title: An exploration of people with Type 1 Diabetes Mellitus (T1DM) experiences of self management during an admission to the acute care setting with a primary diagnosis other than T1DM

Project No.: **5066** Final Approval Date: 21 December 2010 Approval Expiry Date: **4 January 2014**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

If you have any outstanding permission letters (item D8), that may have been previously requested, please ensure that they are forwarded to the Committee as soon as possible. Additionally, for projects where approval has also been sought from another Human Research Ethics Committee (item G1), please be reminded that a copy of the ethics approval notice will need to be sent to the Committee on receipt.

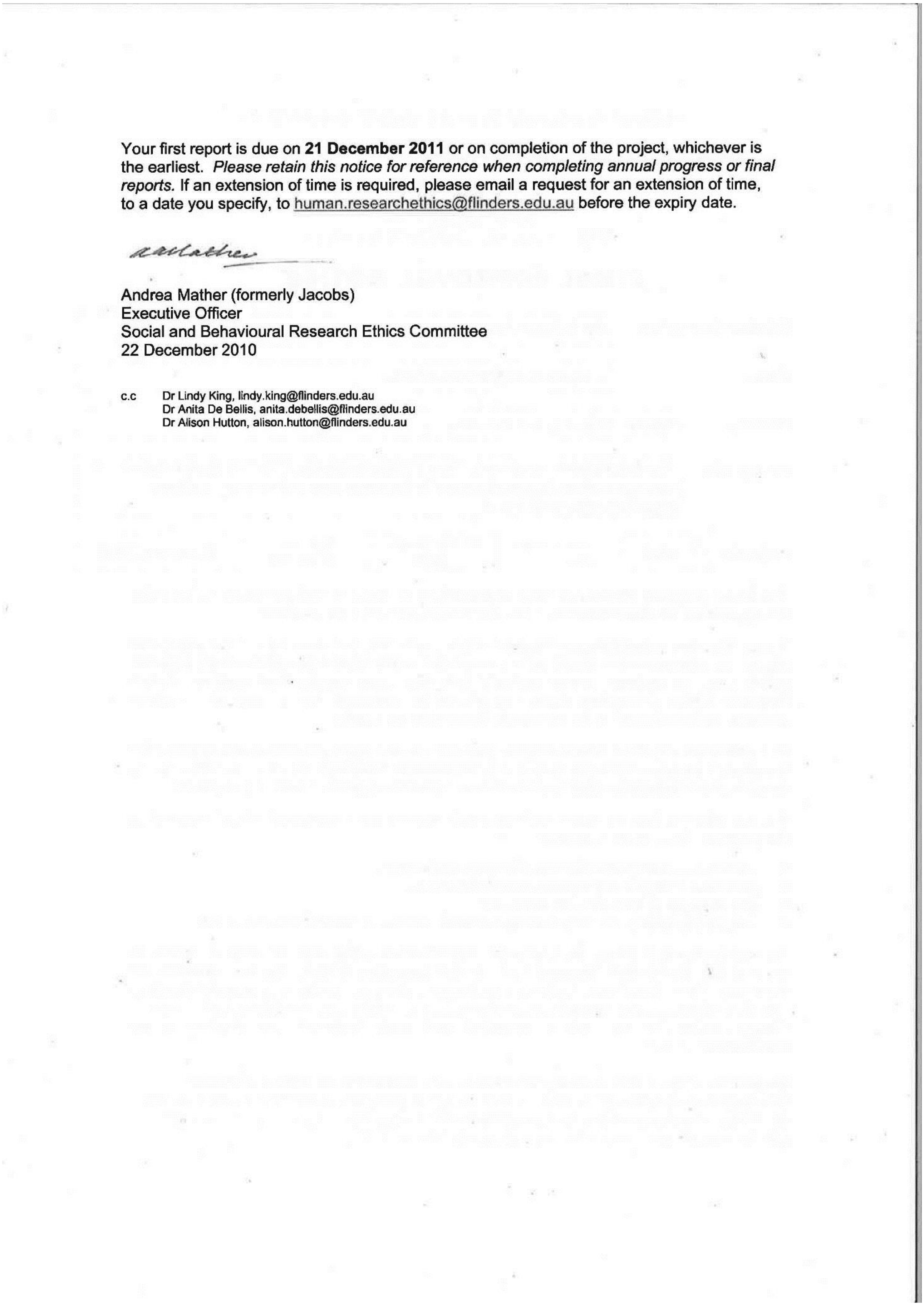
In accordance with the undertaking you provided in your application for ethics approval for the project, please inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion.

You are also required to report anything which might warrant review of ethical approval of the protocol. Such matters include:

- serious or unexpected adverse effects on participants;
- proposed changes in the protocol (modifications);
- any changes to the research team; and
- unforeseen events that might affect continued ethical acceptability of the project.

To modify/amend a previously approved project please either mail or email a completed copy of the Modification Request Form to the Executive Officer, which is available for download from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-and-behavioural-research-ethics-committee/notification-of-committee-decision.cfm. Please ensure that any new or amended participant documents are attached to the modification request.

In order to comply with monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress and/or final report must be submitted. A copy of the pro forma is available from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-behavioural.cfm.



Your first report is due on **21 December 2011** or on completion of the project, whichever is the earliest. *Please retain this notice for reference when completing annual progress or final reports.* If an extension of time is required, please email a request for an extension of time, to a date you specify, to human.researchethics@flinders.edu.au before the expiry date.

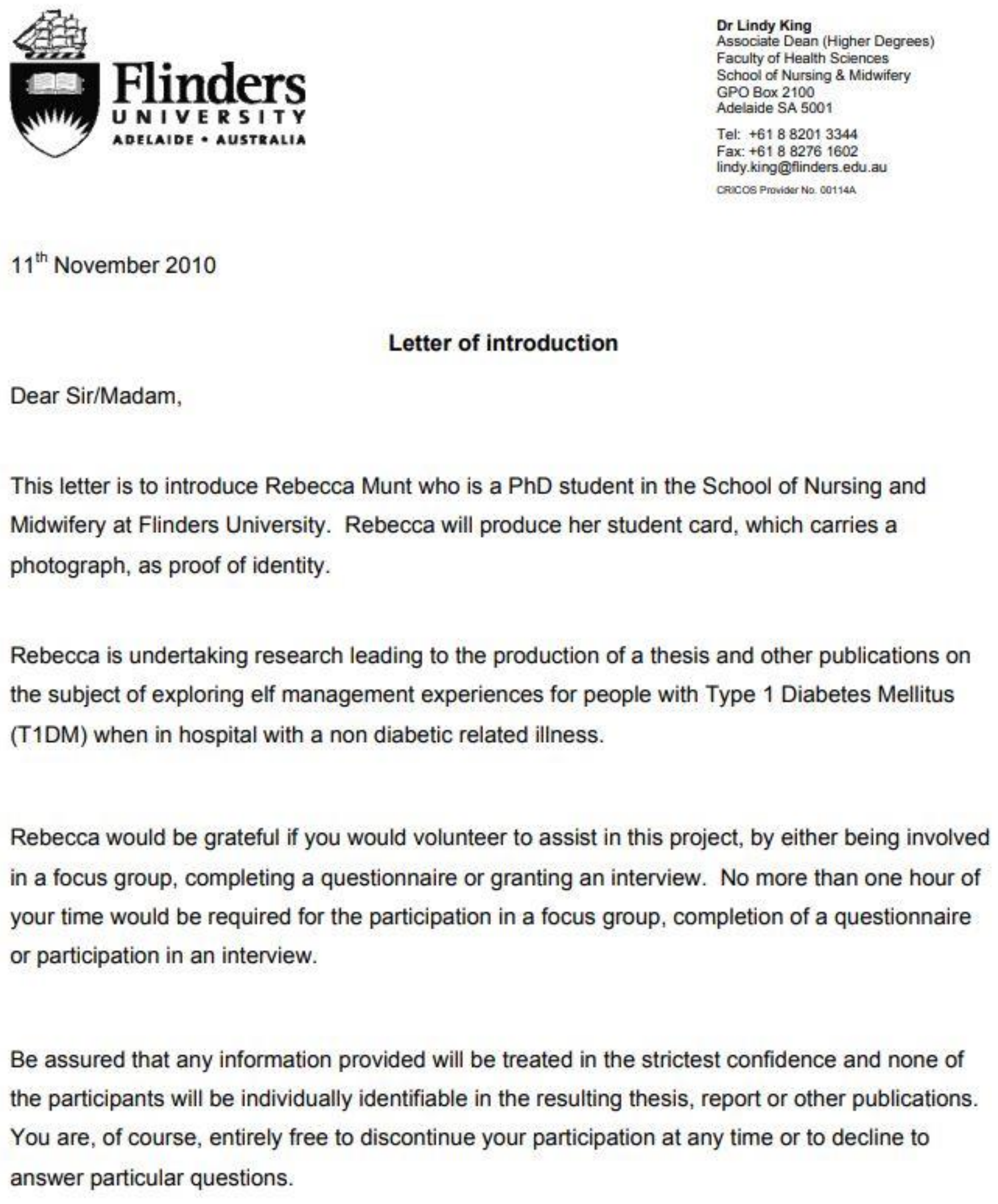
AMather

Andrea Mather (formerly Jacobs)
Executive Officer
Social and Behavioural Research Ethics Committee
22 December 2010

c.c Dr Lindy King, lindy.king@flinders.edu.au
Dr Anita De Bellis, anita.debellis@flinders.edu.au
Dr Alison Hutton, alison.hutton@flinders.edu.au

Appendix 5

Letter of Introduction



Flinders
UNIVERSITY
ADELAIDE • AUSTRALIA

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CRICOS Provider No. 00114A

11th November 2010

Letter of introduction

Dear Sir/Madam,

This letter is to introduce Rebecca Munt who is a PhD student in the School of Nursing and Midwifery at Flinders University. Rebecca will produce her student card, which carries a photograph, as proof of identity.

Rebecca is undertaking research leading to the production of a thesis and other publications on the subject of exploring elf management experiences for people with Type 1 Diabetes Mellitus (T1DM) when in hospital with a non diabetic related illness.

Rebecca would be grateful if you would volunteer to assist in this project, by either being involved in a focus group, completing a questionnaire or granting an interview. No more than one hour of your time would be required for the participation in a focus group, completion of a questionnaire or participation in an interview.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since Rebecca intends to make a tape recording of the focus group and interview, she will seek your consent, on the attached form, to record the interview, and to use the recording or a transcription in preparing the thesis, report or other publications. Please be assured your name or identity is not revealed. It may be necessary to make the recording available to secretarial assistants for transcription, in which case your personal information will be de-identified prior to transcription.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (8201), fax (82761602) or e-mail.

Thank you for your attention and assistance.

Yours sincerely

Lindy King (Dr)

Senior Lecturer in Nursing

Appendix 6

Participant Information Sheet a- Focus Group

PARTICIPANT INFORMATION SHEET – Focus Group

“Exploring daily self management experiences for the person with Type 1 Diabetes Mellitus (T1DM) in hospital”

I am a Registered Nurse currently enrolled at Flinders University in a PhD (Doctor of Philosophy). You are invited to be part of a research project (a requirement of my studies) exploring the experience of self management for people with Type 1 Diabetes in the hospital environment.

This study may not benefit you directly but may lead to a better understanding of how people would like their T1DM managed while in hospital.

The study will involve you participating in a focus group to develop and pilot a questionnaire. The focus group will involve a group of 4 people with T1DM who have recently been to hospital. Participation in the focus group requires you to discuss your thoughts of self management in the acute care setting using an existing draft questionnaire. The questionnaire includes questions about you, your self management practices and the last experience you had in the hospital setting. The discussion will be audiorecorded by the researcher. Your discussion will help to further develop the questionnaire that is to be used in another phase of this study. The focus group will require one hour of participation and the questionnaire will take approximately 45 minutes to complete. You may decline to answer any question(s) that you wish.

If you chose to participate an email or letter will be sent to you after the focus group and development of the questionnaire. The email or letter will thank you for your participation and will inform you of the opportunity to request a summary of the results when the study is finalised.

Your involvement in this study is entirely voluntary and if you chose not to participate it will not affect you in any way. Should you decide to withdraw from the study you may do this freely and without prejudice.

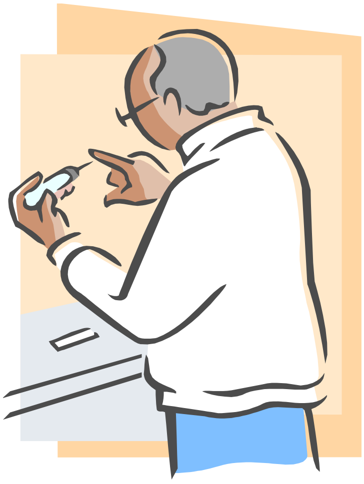
All personal information will remain confidential and no information which could lead to your identification will be released. Information from this study will be used for the completion of the PhD thesis and publication in journals.

All records containing personal information will remain confidential and no information which could lead to your identification will be released. You will be allocated a pseudonym name to ensure confidentiality. All information collected will be stored in a locked cabinet in my office for the duration of the research project. On completion of the study all the information about you will be stored in a locked facility in the School of Nursing and Midwifery for five years. After the five years all information will be confidentially destroyed. Information from this study will be used for the completion of the PhD thesis and for publication.

The researcher is obliged to inform appropriate personnel (Social and Behavioural Research Ethics Committee) if unethical or unsafe practices become apparent.

Should you have any questions about the project, before, during or after the study, you may contact me (Rebecca Munt) on (08)82015749 (Work) or rebecca.munt@flinders.edu.au.

This study has been reviewed by the Flinders University Social and Behavioural Research Ethics Committee. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer - Research (Tel: (08) 8201-3116).



This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5066). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

Participant Information Sheet b- Interview

INFORMATION SHEET

Interview participants

Title: ‘Exploring daily self management experiences for the person with Type 1 Diabetes Mellitus (T1DM) in hospital’

Researchers:

Miss Rebecca Munt

School of Nursing and Midwifery
Flinders University

Ph: +61 8 82015749

Supervisor(s):

Associate Professor Alison Hutton

School of Nursing and Midwifery

Flinders University

Ph: +61 8 82013429

Description of the study:

I am a Registered Nurse currently enrolled at Flinders University in a PhD (Doctor of Philosophy). You are invited to be part of a research project (a requirement of my studies) exploring the experiences of self management for people with Type 1 Diabetes in the hospital environment when T1DM is not the primary admission diagnosis. This project is supported by Flinders University School of Nursing and Midwifery.

Purpose of the study:

The aim of the study is to explore the experiences of self management of the person with T1DM in the hospital setting.

The objectives of the study are:

1. To understand the usual self management practices of the person with T1DM out of hospital

2. To explore the person's perspective of their T1DM management and/or self management experience while in hospital

3. To investigate the factors in the hospital setting which influence T1DM management

What will I be asked to do?

The study will require your involvement in an interview which can be done over the phone or in person. If you are willing to be interviewed I will contact you to arrange a mutually convenient time and place to conduct the interview. The interview duration is estimated to be one hour. You may answer ‘no comment’ or refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences. The interview will be audio recorded. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file and then destroyed once the results have been finalised.

What benefit will I gain from being involved in this study?

The sharing of your experiences may not benefit you directly but may lead to a better understanding of how people with T1DM want their diabetes managed while in hospital.

Will I be identifiable by being involved in this study?

All personal information will remain confidential and no information which could lead to your identification will be released. You will be allocated a pseudonym name to protect your identity. All information collected will be stored in a locked cabinet in my office for the duration of the research project and on my password protected computer. On completion of the study all the information about you will be stored in a locked facility in the School of Nursing and Midwifery for five years. After the five years all information will be confidentially destroyed. Information from this study will be used for the completion of the PhD thesis and publication in journals.

Are there any risks or discomforts if I am involved?

The investigator anticipates minimal risk from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with me.

How do I agree to participate?

Participation is voluntary. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and send it back to me via post or email. Should you have any questions about the project, before, during or after the study, you may contact me on (08) 82015749 or at rebecca.munt@flinders.edu.au.

How will I receive feedback?

After the interview is concluded an email or letter will be sent thanking you for your participation. The email or letter will inform you that you can request a summary of the results when the study is finalised.

Thank you for taking the time to read this information sheet and I hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 5066). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 7

Informed consent forms a – Focus group

CONSENT FORM FOR FOCUS GROUP

I, ...hereby consent to my involvement in the research project entitled: " An exploration of people with Type 1 Diabetes Mellitus (T1DM) experiences of self management during an admission to an acute care setting with a primary diagnosis other than T1DM ".

1. The nature and purpose of the research project described on the attached Information Sheet has been explained to me. I understand it and agree to take part.

2. I acknowledge that Rebecca Munt will be asking me about my experience with T1DM in hospital, that the discussion will be audio recorded and will take up to 60 minutes. I also acknowledge that I will be involved in a discussion with other people with T1DM and the discussion is to remain confidential.

3. I understand the researcher will use a tape recorder to gather data and information obtained will remain confidential.

4. I give permission for the use of data on my Type 1 Diabetes management in hospital to be used in the completion of a research thesis and publication.

5. I understand that while information gained in this study may be published, I will not be identified and information will be confidential.

6. I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researcher in any respect.

7. I understand that there will be no payment to me for taking part in this study.

8. I declare that I am over the age of 18 years.

9. I am aware that I should retain a copy of the Consent form when completed and the information sheet.

Signed:....................................... Full name:.......................................

Date:...................................

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed:... Title:.......................................

Date:..................................

Informed consent form b – Interview

CONSENT FORM – INTERVIEW

I, ………………………….hereby consent to my involvement in the research project entitled " An exploration of people with Type 1 Diabetes Mellitus (T1DM) experiences of self management during an admission to an acute care setting with a primary diagnosis other than T1DM ”.

1. The nature and purpose of the research project described on the attached Information Sheet has been explained to me. I understand it and agree to take part.

2. I acknowledge that Rebecca Munt will be interviewing me about my experience with T1DM in hospital, that the discussion will be audio recorded and will take up to 60 minutes.

3. I understand the researcher will use an audio recorder to gather data and information obtained will remain confidential.

4. I give permission for the use of data on my Type 1 Diabetes management in hospital to be used in the completion of a research thesis and publication.

5. I understand that while information gained in this study may be published, I will not be identified and information will be confidential.

6. I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researcher in any respect.

7. I understand that there will be no payment to me for taking part in this study.

8. I declare that I am over the age of 18 years.

9. I am aware that I should retain a copy of the Consent form when completed and the information sheet.

Signature of participant Date

Signature of witness

Printed name of witness

I, Rebecca Munt as the primary researcher have described to……………………………… ,

the research project and what it involves. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature Date

Appendix 8

Recruitment for participants a

Advertisement for focus group participants

VOLUNTEERS NEEDED!

Would you like to volunteer an hour of your time for a research project exploring Type 1 Diabetes Management in Hospital? If the answer is yes please read on!

Do you have Type 1 Diabetes?

Are over 18 years of age?

Have you being admitted to hospital in the last 2 years for a condition other than your diabetes? For example have you had elective or emergency surgery that required you to be in hospital?

If you have answered yes to the above questions please feel free to contact me (Rebecca Munt) on (08) 8201 5749 or rebecca.munt@flinders.edu.au to discuss your involvement in this important research project.

This image has been removed due to copyright restrictions

This project has been approved by the Flinders University Social and Behavioural Research Ethics Committee.

Recruitment for participants b

Advertisement for interview participants

Would you like to volunteer an hour of your time for an interview for a research project exploring Type 1 Diabetes self-management in hospital? If the answer is yes please read on!

Do you have Type 1 Diabetes?

Are over 18 years of age?

Have you being admitted to hospital in the last 2 years for a condition other than your diabetes? For example, have you had elective or emergency surgery which required you to be in hospital?

If you have answered yes to the above questions please feel free to contact me, Rebecca Munt, on **(08) 8201 5749** or **rebecca.munt@flinders.edu.au** to discuss your involvement in this important research project.

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Appendix 9

Draft interview questions for Focus group

Your self management

The following questions are to help me understand what self management means to you and how you manage your Type 1 diabetes each day. This information is useful for me to understand what is normal for you in your own environment.

Can you tell me what self management means to you?

Could you please describe your typical daily self management routine?

What happens if your typical routine is interrupted?

What are the main factors that affect your decisions about your diabetes management?

Your experience of T1DM in hospital

The following questions are to help me understand you actual experience in relation to your diabetes management while you were in the hospital.

Please tell me about any discussion you had about your diabetes management with the health professionals during your hospital stay.

What was the first day in hospital like in relation to your diabetes management?

What changed since the first day in relation to your diabetes management?

If you had never been admitted to hospital before for an illness unrelated to your diabetes is the treatment received what you expected?

As your condition improved did your diabetes management change?

How do you feel about managing your Type 1 Diabetes when hospitalised?

Did you want to continue self managing your T1DM in hospital? If so why? If not, why not? Please explain

What do you think impacts on your ability to self manage your T1DM in the hospital setting?

What do you think is managed well in the hospital setting in relation to your diabetes?

What do you think isn't managed well in the hospital setting in relation to your diabetes?

The hospital environment

What do you think are the rules about managing Type 1 Diabetes in the hospital?

How did you find out about the rules?

Did the nurses or doctors talk to you about the rules on managing Type 1 Diabetes in the hospital?

Did you have access to your own diabetes equipment in hospital?

Was the hospital environment supportive of you managing your own diabetes?

Please tell me about your experience with the nurses and doctors in the hospital setting?

Do you believe the nurses and doctors had sufficient knowledge to provide care for your T1DM in the hospital setting?

Please comment on any education you gave to the nurses or doctors on your diabetes management.

Did you feel confident that the nurses and doctors were able to competently care for your diabetes?

Please explain whether you felt included by the nurses and doctors in relation to your diabetes management?

What aspects of diabetes management in the hospital setting, if any, would you like to see improved?

How do you think your diabetes management in hospital could be improved?

Do you have any concerns regarding future hospitalisations?

Can you please describe what knowledge and ability you feel you need to be an active participant in your T1DM management in hospital?

Can you describe any specific incident that occurred regarding your T1DM management in hospital?

Are there any other issues about your diabetes management in hospital that you would like to discuss?

Appendix 10

Initial broad interview questions

Your self-management

The following questions are to help me understand what self-management means to you and how you manage your Type 1 diabetes each day. This information is useful for me to understand what is normal for you in your own environment.

Can you please explain to me what self-management means to you?

Could you please describe your typical daily self-management routine?

Please tell me about what happens to your diabetes management if you are not able to maintain your typical daily self-management routine?

Can you please explain to me what influences you in your daily management of your diabetes?

Hospital specific questions

The following questions are to help me understand your experience of self-management in the hospital setting.

Can you please tell me about your most recent experience of managing your type 1 diabetes when you were in hospital?

Can you please tell me how you feel about managing your type 1 diabetes when in hospital?

Can you explain from your most recent hospital admission if you did anything to prepare to manage your diabetes while in hospital?

Can you tell me your recent experience you had with managing your diabetes if your admission to hospital was not planned? (default question for an Emergency admission)

Can you tell me about any about your interactions with the health professionals in hospital related to managing your diabetes?

Is there anything else about your experience of managing/ self-managing your diabetes in hospital you would like to share? Anything you feel I have missed?

Appendix 11

Demographic questions prior to interview

Thank you for agreeing to complete the following questions on you and your Type 1 Diabetes.

The following questions are to help me gain an understanding of you as an individual and your diabetes history. The information will not be used to identify you as an individual.

Demographic data

Age: 18 -28 ☐ 29 – 38 ☐ 39 – 48 ☐ 49 – 58 ☐ 59 – 68 ☐ 69 – 78 ☐ over 79 ☐[18]

Gender: Male ☐ Female ☐ Other ☐

Highest education level: High School ☐ Tafe ☐ University ☐ Other ☐

Current Occupation:

Postcode:

Diabetes History

Age of onset of Type 1 Diabetes Mellitus?

Type of insulin used?

Device used to administer insulin?

How many BGLs do you do per day at home?

What was your last HbA1c?

Do you completely manage your care or do you have help?

Can you please list your medical history?

What other medications do you take on a daily basis?

Do you completely manage your Diabetes care or do you have help?

---

[18] Originally age range provided for participants on the suggestion by Charmaz (2014) but later followed up actual age with participants to accurately determine years lived with T1D. All participants were happy to provide actual age at time of interview.

Hospital admission

The following questions are to help me to understand your experience in your most recent hospital admission.

When were you admitted to hospital (must be within the last 2 years)?

2017 ☐ 2016 ☐ 2015 ☐ 2014☐ *(date altered dependent on interview date to fit 2 year criteria)*

Why were you admitted to hospital?

What was your admission diagnosis?

Was it a planned admission to hospital or an emergency admission?

Planned ☐ Emergency ☐

Was the hospital a public or private?

Public ☐ Private ☐

If the admission was planned did you attend a pre admission appointment at the hospital?

Yes ☐ No ☐

If you answered yes to the previous question was your diabetes management discussed at the pre admission appointment?

Yes ☐ No ☐

How long were you in hospital for that admission?

Overnight ☐ 1 -2 days ☐ 3 – 4 days ☐ 5 – 6 days ☐ 7 – 8 days ☐

Appendix 12

Additional specific questions to the broad interview questions

Hospital specific questions

The following questions are to help me understand your experience of self management in the hospital setting.

Can you please tell me about your most recent experience of self-managing your type 1 diabetes when you were in hospital?

Can you explain to me how you made the decision to self-manage your type 1 diabetes in hospital?

Can you please describe what knowledge and ability you feel you need to be an active participant in your T1DM management in hospital?

Were there any specific supports in place, or that you needed in place, to be able to self-manage?

What do you think the knowledge level of the health professionals was about your diabetes self-management?

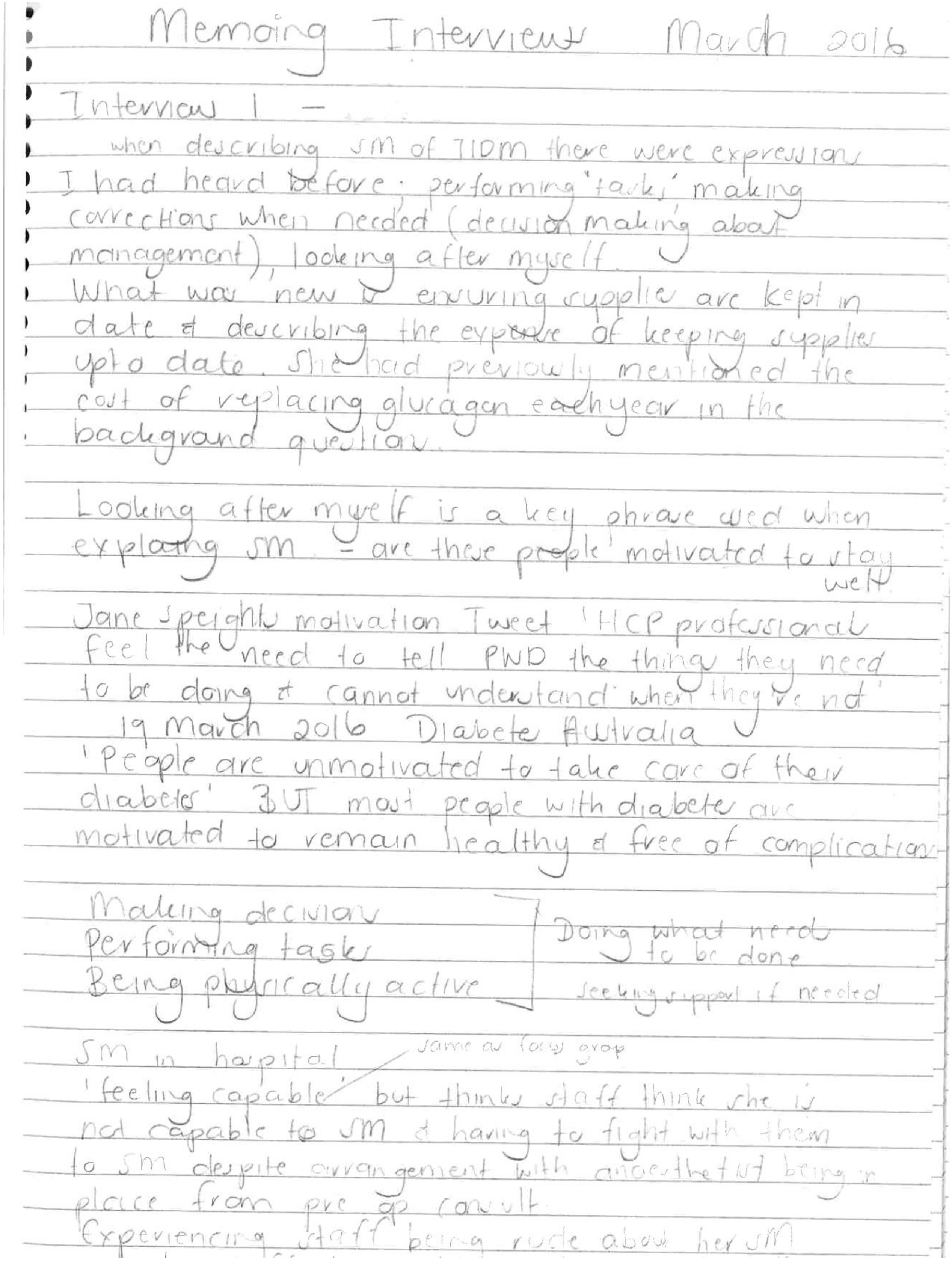
Do you feel like you had to provide education to the staff while you were in hospital on aspects of your self-management?

How do you think that health professionals could better support people with type 1 in the hospital setting?

Is there anything else about your experience of managing/self-managing your diabetes in hospital you would like to share? Anything you feel I have missed?

Appendix 13

Memo after first interview (handwritten)



Memoing Interview March 2016

Interview 1 –

when describing SM of T1DM there were expressions I had heard before: performing 'tasks' making corrections when needed (decision making about management), looking after myself.
What was new is ensuring supplies are kept in date & describing the expense of keeping supplies up to date. She had previously mentioned the cost of replacing glucagon each year in the background question.

Looking after myself is a key phrase used when explaining SM – are these people motivated to stay well

Jane Speight's motivation Tweet 'HCP professionals feel the need to tell PWD the things they need to be doing & cannot understand when they're not'
19 March 2016 Diabetes Australia
'People are unmotivated to take care of their diabetes' BUT most people with diabetes are motivated to remain healthy & free of complications

Making decisions
Performing tasks
Being physically active
Doing what needs to be done
seeking support if needed

SM in hospital
same as focus group
'feeling capable' but thinks staff think she is not capable to SM & having to fight with them to SM despite arrangement with anaesthetist being in place from pre op consult
Experiencing staff being rude about her SM

Did own BGLs & recorded on BGL chart. Would share info with nurses if they asked. Why weren't the nurses asking /reviewing the chart? Perfect opportunity to discuss management with patient & what is normal for her.

If not aware of BGL's how would they know if her insulin dose was effective? Are they linking hyper to reduced wound healing, ↑ risk of post op infection, risk of ↑ LOS, ↑ cost to hospital / government etc

Point of consumer focused care of ACSQHC is partnering with consumers; no partnering here in relation to managing T1DM in hospital = could lead to harm for patient, could lead to education for patient if needed or staff

Preparing to manage – need to know if it makes a difference if planned or unplanned admit.

- choosing easy to manage pump
- taking own equipment

being prepared is about responsible management of T1DM when not at home so plausable to think they would take responsibility in another setting

★ is it being prepared or taking responsibility using knowledge & experience ★

experiential knowledge

Kept equipment & chose not to tell ~~other~~ HPs due to hearing & reading about others experience in hospital

– look at background history – maybe add question if past experience shaped current experience

★ – need to explore if first experience or if prior experience makes a difference in preparation or wanting to SM

Being unable to manage due to part of vomiting & feeling unwell but when well knowing HP management was not good as BGL's elevated, ketone not checked and pt unsure as to why she felt unwell
- ? limited communication at this time about managing diabetes - unable to advocate for self
- no pre admission appt ? no plan documented
- lead to letter of complaint about T1DM been written
- management with a response of you werent sick enough for ketone testing - a vomiting person with T1DM & ↑ BGL should set an alarm bell for DKA & the need for ketone testing which patient knew but staff didn't

As a result when back on pump needed to manipulate insulin delivery to reduce BGL - would staff have just left BGL to remain high? pt had no DE or Endo r/v in hospital so staff not likely to have consulted with DE or Endo either about ↑ BGLs - are staff still scared of hypos - p 7.

When experiencing ↑ BGL's once managing herself she didn't feel as worried as she knew what she was doing.

On p.2 - seeking HP support when experiencing unexplained BGL
want to SM
The irony of this - 'I was telling them what to do.' - while with HP.
But also says if able to SM in hospital she would seek HP support if unable to manage or if needing support so shows decision making when unsure include HP support

Chose to use an older pump while in hospital as she was more familiar with her older pump. Made the decision to use the older pump when preparing to go into hospital & having the decision to ensure sm was easier as she wouldn't have to deal with issues with a pump 'Didn't want to have a pump I had to think about'. Didn't want to add to ? stress/burden of managing diabete outside of familiar home setting

(taking responsibility)
(decision making)

Took own supplies - taking own equipment + extras
- being prepared
- knowing what to take

Chose to take this equipment with her because that is normal practice for her to take the equipment/kit when she leaves the house ∴ an automatic response to leaving home is to take sm equipment

Shows ability to be able to prepare to sm in hospital - no one asked her to bring stuff.

- Chose to hide equipment due to others bad experiences.

The irony of this is person with T1DM wants to sm & they arrive at hospital prepared to sm with all their equipment then chose to hide as worried HP will take equip away. However if there wasn't the fear of having equipment removed then staff might see how prepared & capable people are to sm in hospital by what they have brought with them. Could lead to open conversation about management of T1DM in hospital rather than T1DM management being hidden & patients choosing to lie to HP by hiding equip. Opportunity for collaborative care being missed & for staff to learn from patient

When HP were managing T1DM the BGL's were being run at a much higher level than the patient would have liked – due to being post op wasn't able to have those conversations once SM the patient had to manipulate pump to bring ↑ BGL down.
Pre op patient told about having to have tight control but then felt no one was concerned about ↑BGL post op except the patient once she became aware (no ketone test)

Hypo experience
Other patients experience

Appendix 14

Advocating for self memo 28 November 2017

What does it mean?

All of the participants at this point of data collection have all spoken about the need to advocate for themselves in the hospital setting. The participants feel the need to express to the health professionals how they will manage their diabetes or what they need to do to manage their diabetes in order to keep them safe and well; BGL within normal range for them or insulin doses based on needs or anticipated needs dependent on what is happening at the time. The participants expressed if they don't speak up and advocate for their own diabetes management then there is not someone who will do it for them and often there is a conflict between what the health professional suggests and what the participants years of lived contextual experiences suggests.

As suggested by KC *losing your voice* occurs in the hospital setting when you are in the patient role and as a HP herself she wonders how those who do not understand the health system manage to advocate for themselves. Feeling protective and being in control of themselves really forces the person to advocate for themself even when they are not a health professional. An example of a non HP participant is below where she is suggesting the need to advocate for herself

Only that's it's important to be, not aggressive, but you have to push the fact that you can do it (Jane).

To add to this the above participant wrote a letter of complaint to the hospital knowing that her experience would not change but she was advocating for others who will be in the same situation as herself in the future as she wanted to see improvements in care to the person with T1DM in hospital.

The reason for advocating for themselves is to protect themselves from harm or potentially in order to protect themselves from harm they are advocating for themselves.

The participants are fighting for control of their diabetes, which they have daily outside of the hospital setting, when they advocate to keep themselves safe from harm.

The participants also need to advocate for themselves as they are often feel they are being judged or misjudged by the health professional about their capacity to self-manage and their level of expertise around their own self-management and how well they understand their bodies responses to change based on their years of contextual experience and based on previous hospital admissions which they have learnt from. The HP is also seen as not recognising the individuality of each person's T1DM and that the body does not match the text book so the advice the HP provides is determined to be incorrect or unsafe. Jane acknowledged the health professionals have training about diabetes but also identifies they don’t know her and her diabetes like she does.

What does it look like?

Advocating for self means the participants are ‘politely’ disagreeing with or *respectfully challenging* the health professionals suggestions on insulin doses or BGM. The participants are listening to what the health professional suggests and considering what they are saying then anticipating what will occur if they follow the health professionals’ advice. The participants are relying on their previous experience when they anticipate what following the HPs advice will do to their diabetes management and then they are making an informed decision based on their experience and then telling the health professions if I do….. then this will happen so I choose to do …. The participants are then *asserting their expertise* and telling the HP what they will do

What are the barriers/facilitators?

An aspect of advocating for themselves is to inform and potentially educate the health professional on how a pump or CGM works.

Losing voice as a patient

Not being listened to lead to the participant just doing their own thing and not consulting with the HPs about how they are managing.

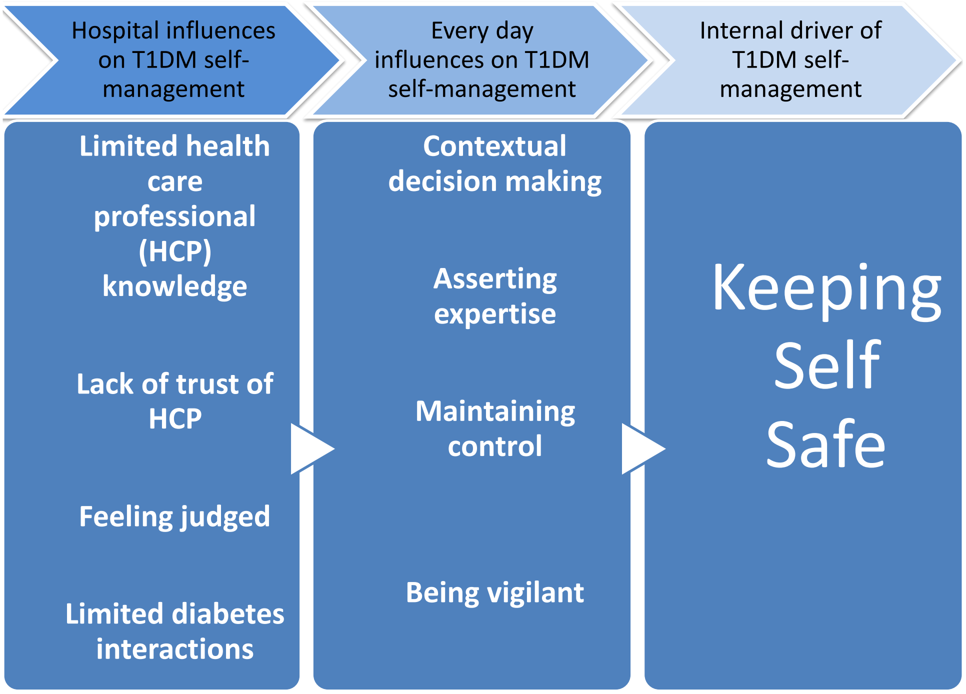
Knowing HPs don’t have a good level of understanding of T1DM

Appendix 15

Preliminary conceptual model January 2018

Appendix 16

Final conceptual model and summary for participants



Conceptual model of the substantive grounded theory of *Keeping Self Safe*

Hospital influences

The first component of the model includes the external influences which impacted on the participants' self-management in hospital. These external influences impacted on the participants' actions and the meanings they gave to their interactions with health professionals while in hospital, directly related to the self-management of their T1DM. The categories which were specific hospital influences are *limited health professional knowledge* on self-management of T1DM, *lack of trust* of the health professional to provide appropriate care, the participants *feeling judged* by the health professional around self-management of their T1DM, and having *limited diabetes interactions* with the health professionals. The direction of the arrow from this component of the conceptual model shows the relationship the external hospital influences have on the actions of the participants in response to their experience of self-managing their T1DM in hospital.

Every day influences

The second component of this model identifies the internal influences participants with T1DM relied on to effectively self-manage their T1DM in the hospital. There was a reliance on the skills and knowledge the participants had developed to self-manage their T1DM every day outside of the hospital setting, which they were then applying in the hospital setting in response to the external hospital influences. The categories which were specific to the everyday influences included using *contextual decision making* around self-management, participants *asserting expertise* based on their experiential knowledge of their T1DM, *maintaining control* of their chronic condition, and *being vigilant* in response to maintaining target range BGLs. The arrow from this component of the conceptual model demonstrates the categories from the everyday influences leads to the main internal driver for all of the actions and decisions around self-management of T1DM in hospital which is the core category of *Keeping Self Safe*.

Internal driver

The core category, *Keeping Self Safe*, was central to explaining the rationale behind the participants' actions in relation to self-managing their T1DM in hospital. Each of the categories within the hospital specific influences compelled the participants to rely on their everyday self-management construction which ultimately influenced the core category as the actions taken by the participants in hospital to keep themselves safe were based on what they do every day to manage their T1DM in order to prevent themselves from being harmed in hospital.

Appendix 17

Framework for understanding diabetes-related stigma

Browne, J, Ventura, A, Mosely, K & Speight, J 2014, ‘‘I’m not a druggie, I’m just a diabetic’: a qualitative study of stigma from the perspective of adults with type 1 diabetes’, *BMJ Open*, vol. 4, iss. 7, pp. 1 – 10.

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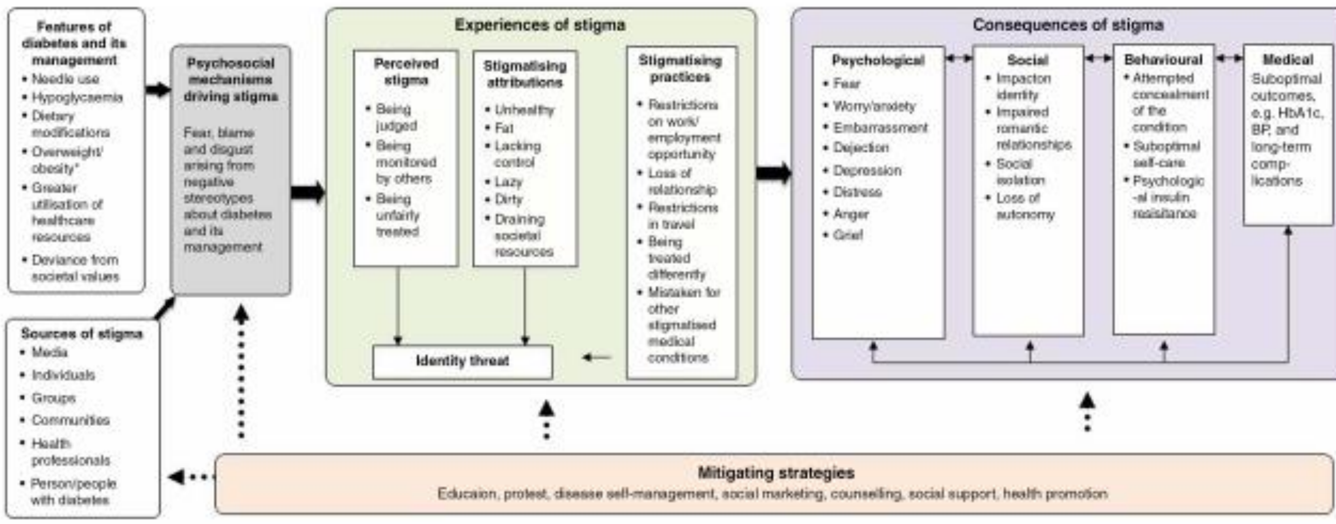
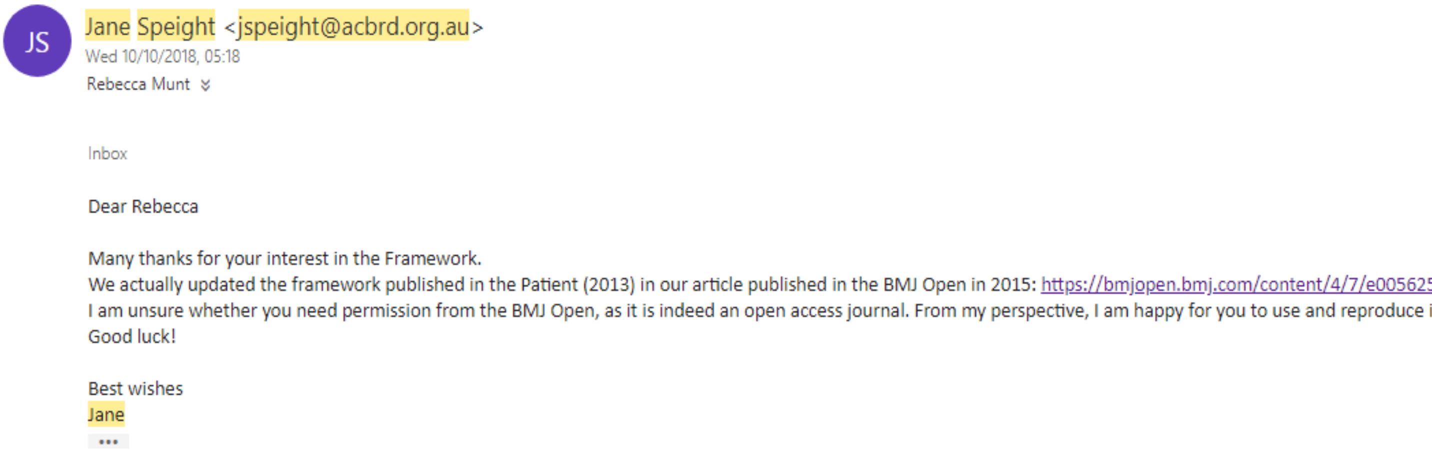


*Type 2 diabetes only

Figure 1 Revised framework to understand diabetes-related stigma.



JS Jane Speight <jspeight@acbrd.org.au>
Wed 10/10/2018, 05:18
Rebecca Munt

Inbox

Dear Rebecca

Many thanks for your interest in the Framework.
We actually updated the framework published in the Patient (2013) in our article published in the BMJ Open in 2015: https://bmjopen.bmj.com/content/4/7/e00562
I am unsure whether you need permission from the BMJ Open, as it is indeed an open access journal. From my perspective, I am happy for you to use and reproduce
Good luck!

Best wishes
Jane

Appendix 18

Follow up Interview questions via email about discharge planning (October 2017)

My question is did any of the health professionals talk to you about how you would continue to manage your diabetes at home after you were discharged from hospital especially considering you had a corticosteroid injection which impacted on your BGLs?

If they did discuss managing your diabetes after leaving hospital what did they say?

If they didn't discuss managing your diabetes at home after leaving hospital do you think they needed to?

Did you need to do anything differently once you arrived home from your usual self-management?

Appendix 19

Word version of publication of a peer reviewed article

Munt, R, Hutton, A, Zannettino, L & Giles, T 2018, 'The experience of type 1 diabetes self-management in hospital: a constructivist grounded theory' *Australian Diabetes Educator*, vol. 21, no. 4.

The experience of type 1 diabetes self-management in hospital: a constructivist grounded theory

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Abstract

Background: People with type 1 diabetes (T1D) are responsible for their complex self-management and over time become expert self-managers. However, on admission to hospital they are often required to relinquish their capacity for self-management, and their expertise of their condition is not acknowledged by health professionals (HPs).

Aim: To explore the experiences of self-management for the adult with T1D in hospital, with a primary admission diagnosis other than diabetes, and construct a grounded theory of self-management.

Methods: The generation and analysis of data were guided by Charmaz's constructivist grounded theory methods, which include coding and constant comparative analysis. Fifteen people shared their self-management experiences during one focus group, 12 in depth interviews and three follow- up interviews.

Results: People with T1D experience a range of influences on their self-management capacity in hospital. Influences specific to the hospital include lacking trust in HPs and the perceived knowledge deficit HPs have of T1D management. As a consequence those with T1D rely on their everyday self-management strategies and practices, such as contextual decision making, to self-manage their diabetes in hospital. The overall internal driver to keep themselves safe in hospital was brought about by both the everyday practices of diabetes self-management and the practices of HPs.

Conclusions: The self-management expertise of the person living with T1D needs to be acknowledged and valued by HPs. Instead of dismissing their expertise, HPs need to form meaningful partnerships with the person with T1D to ensure they remain safe in the hospital setting.

Introduction

People living with T1D are responsible for the intricate self-management of their chronic condition. Self-management typically includes blood glucose monitoring, making dietary choices, undertaking physical activity and administering insulin, along with making over 100 diabetes related decisions every day (1). Over time people with T1D are known to become expert self-managers (2 -4). However, on admission to hospital this expertise is often dismissed and people are expected to relinquish control over their diabetes self-management to HPs (5 -7). Despite this expectation, the literature suggests HPs have a 'poor' knowledge of T1D management (5- 13). Considering the expertise of people to self-manage their diabetes together with the poor knowledge of HPs in managing T1D, it would seem reasonable to suggest that those with T1D need to be supported to continue to self-manage their diabetes in hospital. However, minimal research exists on T1D self-management in hospital (14).

Purpose of study

The purpose of this study was to explore the self-management experiences of adults with T1D while in hospital with a primary admission diagnosis other than diabetes. The study also aimed to generate a substantive grounded theory to explain their experience as there are no known theories on the individual's experience in hospital (15).

Methods

Constructivist grounded theory methods were selected as the most appropriate to meet the purpose of the study (16, 17). This qualitative methodology uses a systematic, inductive and comparative approach for undertaking research which leads to the construction of a theory grounded in the data (16). Ethical approval was gained from the appropriate University Social and Behavioural Research Ethics Committee. Purposive sampling was initially used to recruit participants who had been admitted to general medical or surgical wards in hospital and were physically and mentally capable of self-managing. Data was generated through one focus group, 12 in depth interviews and three follow-up interviews (Table 1 and 2). Constant comparison method was used to analyse the data until theoretical data saturation was reached and the substantive grounded theory was generated (16, 17).

[Insert participant tables here]

Results

A conceptual model was developed to represent the categories from the data which led to the construction of the substantive grounded theory (Figure 1). The model represents the external and internal influences which impacted on the participants' actions and the meanings they gave to their interactions with HPs while in hospital, directly related to the self-management of their T1D.

[Insert Figure 1 here]

The first component of the conceptual model includes hospital specific influences on diabetes self-management. Participants indicated HPs did not have sufficient knowledge of T1D. Nicola stated:

> *Going into hospital makes me really nervous…..Because I know that the nurses and the doctors have got no idea about my condition* (Interview 4).

In addition, participants indicated they had a lack of trust in the HPs in hospital to provide appropriate management of their T1D. Trish said:

> *I only trust myself. Trust myself to self-manage …..I don't have the faith in nursing staff to look after my diabetes* (Focus Group)

Some participants experienced HPs judging them as not being capable to self-manage their T1D despite them feeling capable of self-managing.

> *I feel very capable of doing it* (self-management) *but, unfortunately, most of the staff on the surgical wards don't think you are capable of doing it* (Sarah, Interview 1)

Participants also felt there were limited opportunities throughout their episode of care to discuss their diabetes management with HPs, which impacted on their diabetes management. Eve experienced elevated blood glucose levels due to limited discussion with HPs about her treatment:

> *I checked my blood sugars and they were like 14 point something. I sort of looked around like confused. Like what's going on? ….. ‘oh you're on a glucose drip’….I'm like, ‘well I need to correct for that’….They didn't even tell me I was on one* (glucose drip) (Interview 9).

The second component of the conceptual model depicts everyday influences on diabetes self-management. Participants were required to rely on their usual diabetes knowledge and skills to self-manage in hospital.

Participants used contextual decision making based on their experiential knowledge of their T1D to self-manage their diabetes in hospital. Clare suggested she is constantly using information to make decisions about her diabetes self-management.

> *….anything you want to eat, anything you want to drink, you've got to do a blood test and tell your pump. So yeah all through the day it is constantly on my mind....it's just what I do…* (Interview 2).

Participants were also required to rely on their experiential knowledge of their diabetes self-management to assert their expertise around decisions HPs were making about their T1D management. Dave stated:

> *…the* (the Doctor) *said ‘we're going to do this’ and I said ‘hmm, I don't like the sound of that’. I got into quite an argument with ...the orthopaedic registrar and he said ‘yeah, we're going to put you on a continuous drip where we're going to titrate insulin and glucose in these ratios’. I said ‘those ratios are wrong. I want you to use this’. He said ‘no, we're the doctors’. I said ‘no, I am the person with diabetes here and I know my management’* (Interview 11).

Participants felt the need to increase their vigilance to protect themselves in response to feeling HPs had limited knowledge of T1D management and feeling judged by HPs in hospital. Dave stated:

> *I think the vigilance is what we do anyway. I think in hospital we automatically feel like we're going to be judged if we drift too far out of certain limits on our blood glucose - we feel like we're going to be judged on our blood glucose. So do we increase our vigilance to deal with that? Probably* (Interview 11).

Participants also felt the need to maintain control over their diabetes self-management in hospital due to their belief the HPs did not know how to provide appropriate care for their T1D. Lisa said:

> *I informed my surgeons that I am quite capable and confident of doing that* [self-managing]. *I know how to look after my own diabetes I want to be responsible for it* (Focus Group).

The third component of the conceptual model represents the substantive grounded theory generated from the data. *Keeping Self Safe* was central to explaining the participants’ actions in relation to self-managing their diabetes in hospital. The hospital specific influences compelled the participants to rely on their everyday self-management construction in order to prevent themselves from being harmed by HPs in hospital.

Discussion

This constructivist grounded theory study provides insight into the self-management experiences of adults with T1D in hospital. The interactions these adults had with HPs in hospital required them to take actions to keep themselves safe in relation to their diabetes management. Previous hospital experiences also informed how participants constructed their expectations of the care they might receive from HPs during their most recent admission. Keeping themselves safe in relation to their diabetes self-management meant that participants focused on reducing harm from hyperglycaemia or hypoglycaemia or developing infection post-operatively so as not to increase their length of stay.

The current lack of guidelines or evidence to support self-management of T1D in Australian hospitals needs to be addressed (18 - 22). Despite this lack of self-management guidelines, the Australian Commission of Safety and Quality in Health Care (ACSQHC) (23, 24) strongly advocates for partnering with consumers in healthcare in order to improve clinical outcomes. Shared decision making and consumer participation in health care is considered as essential for consumer safety (23, 24). A review by the Sax Institute (15) suggests that in order to improve health care and provide appropriate care, acknowledging and utilising the individual's experience of their care is crucial. Therefore, an understanding of the experience of adults with T1D in hospital is essential in relation to understanding their stance on self-management and to improve the care they receive in hospital.

Credentialled Diabetes Educators (CDEs) working in hospitals could act as advocates for the person with T1D when they are having discussions with HPs around how the individuals' T1D will be managed in hospital (25). They could also encourage HPs to understand the need to develop individualised, collaborative, negotiated plans of care around T1D management in hospital (25). CDEs could support HPs to understand that the person with T1D has expert knowledge which may require a change in attitude from the HPs who are known to be reluctant to trust people's experiential knowledge of their chronic condition (26). CDEs could also assist HPs in hospital by providing them with ongoing education on the use of diabetes technology such as CGM and pumps. Participants in this study indicated they would be willing to help HPs learn about their use of technology in their T1D self-management. Therefore, CDEs could encourage HPs to seek additional understanding of diabetes technology from the individuals with T1D whom they encounter. There also needs to be development of appropriate policies to support people with T1D to self-manage their diabetes in hospital. These should be developed through collaboration between diabetes HPs (including CDEs), other HPs, hospital management and consumers living with T1D (25).

A limitation of this study is the results are not generalisable to all people with T1D. However the rigor used to generate this substantive grounded theory provides a unique insight into the experiences of people with T1D in hospital. Another potential limitation of this study is that all of the participants had previously been admitted to hospital with a primary admission diagnosis other than their T1D, and this may have impacted on their expectations of the care they would receive in subsequent admissions.

Conclusion

Over time people with T1D develop self-management expertise, however this expertise is not always recognised by HPs in hospital. This study found people with T1D admitted to hospital want to continue to self-manage their T1D, as they do every day outside of hospital. This decision is largely due to their perceived need to keep themselves safe from potential harm brought about by HPs who may have a limited understanding of the complexities of T1D management. CDEs are in an ideal position to encourage HPs to accept the individual with T1D as the expert on their diabetes and to collaborate with them to develop negotiated plans of care to improve the safety of those with T1D in hospital.

Acknowledgments

Firstly a huge thank you to the people living with T1D who participated in this study. Without these people sharing their experience this study would not have been possible. Secondly thank you to the ADEA for the opportunity to present the study at the 2018 Australasian Diabetes Congress and thank you to Roche and ADEA for the Best abstract award at the Congress. Finally I would also like to acknowledge my PhD supervisors and say thank you for their invaluable support.

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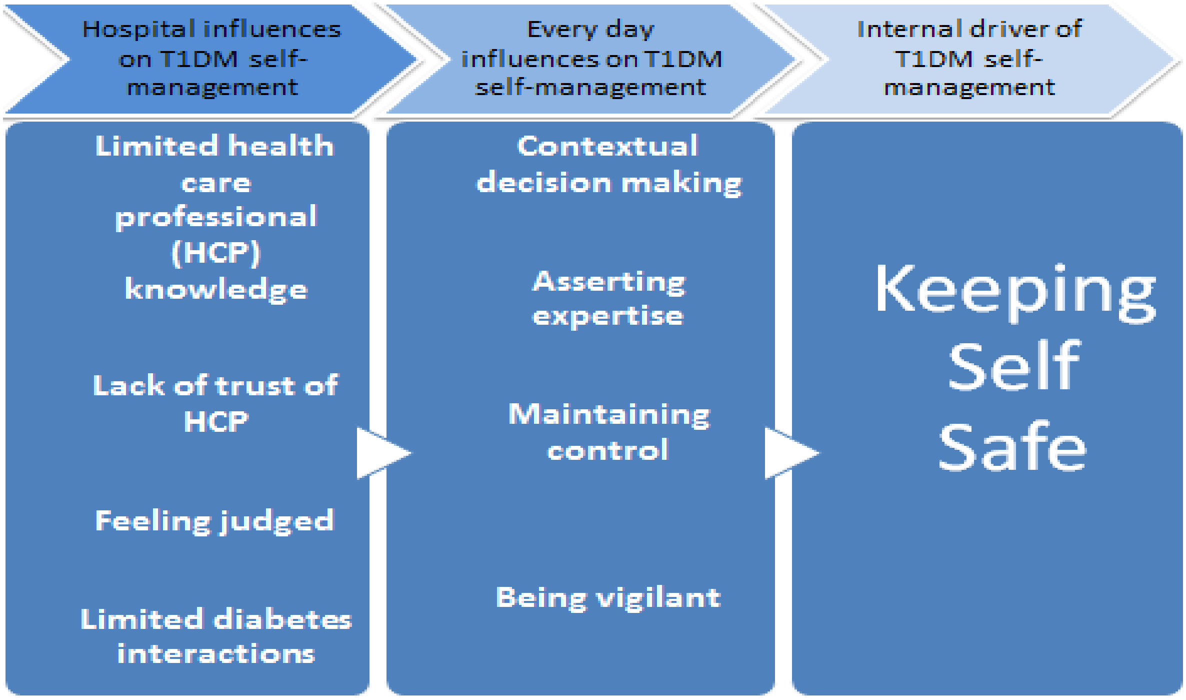


Figure 1. Type 1 Diabetes self-management experience in hospital conceptual model

Table 1. Participants' demographic Focus Group

Pseudonym	Age	Life stage at diagnosis	Insulin delivery method
James	59 - 68	Childhood	Pen
Lisa	29 - 38	Childhood	Pen
Susan	59 - 68	Childhood	Pen
Jane	59 - 68	Adulthood	Pump
Trish *	29 - 38	Childhood	Pump

***Trish same participant in the in depth interviews**

Table 2. Participants' demographic in depth interviews

Pseudonym	Age	Education level	Diagnosis age	Insulin delivery	*BGM/day	HbA1c (% and mmol/mol)
Emma **Int. 12**	39 - 48	Tafe	14	Pump	10 -12	5.8% 40 mmol/mol
Dave **Int. 11 & 15**	49 -58	University	14	Pen	**CGM 1	6.4% 46 mmol/mol
Bianca **Int. 10**	18 -28	Tafe	6	Pump	6	7.3% 56 mmol/mol
Eve **Int. 9**	29-38	University	23	Pump	CGM 3	6.2% 44 mmol/mol
Laura **Int. 6**	59 -68	University	10	Pen	4	7.8% 62 mmol/mol
Trish **Int. 5, 7 & 8**	39 -48	University	10	Pump	CGM 2	6.8% 51 mmol/mol
Nicola **Int. 4 & 14**	39 -48	University	14	Pump	5	7.4% 57 mmol/mol
Kate **Int. 3**	39 -48	High school	13	Pump	4	7.8% 62 mmol/mol
Clare **Int. 2**	39 -48	High school	3	Pump	10 -12	7.9% 63 mmol/mol
Sarah **Int. 1 & 13**	59 -68	University	15	Pump	CGM 4-6	7.1% 54 mmol/mol

*BGM – blood glucose monitoring, **CGM- continuous glucose monitoring

Appendix 20

Social media blog following PhD presentation at Australasian Diabetes Congress (August 2018)

9/3/2019 Diabetes in Hospital #18ADC ResearchTwice Diabetes | Twice Diabetes

Twice Diabetes

Delving into what the Doctors Won't Tell You

Diabetes in Hospital #18ADC Research

September 13, 2018 Uncategorized #18ADC, Australian Diabetes Congress, Rebecca Munt, type 1 selfmanagement in hospital Melinda Seed

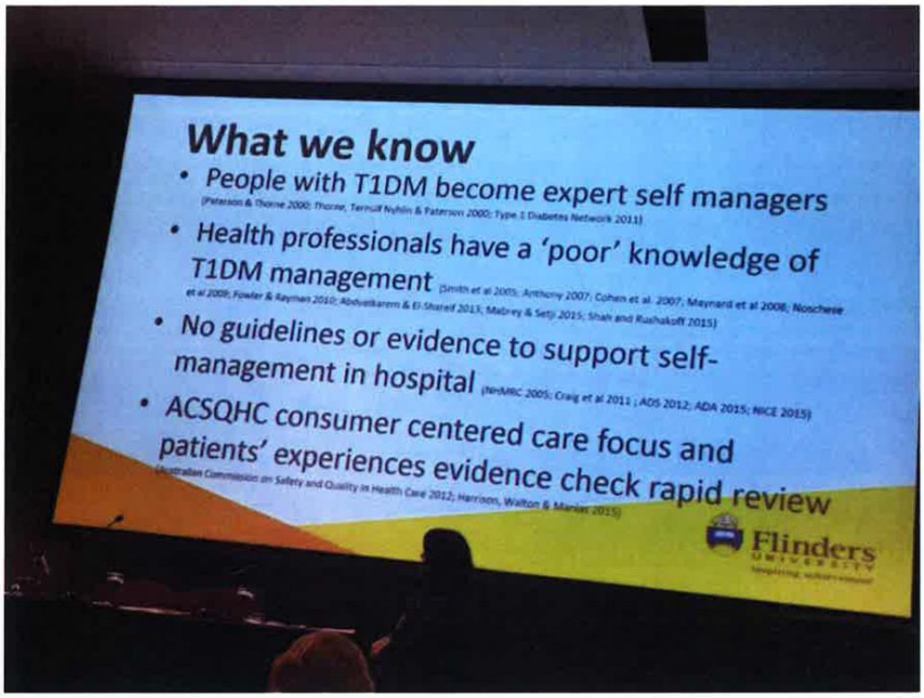
Melinda Seed writes for Twice Diabetes

Diabetes care amongst hospital inpatients, as I mentioned here, was a topic of focus at the recent Australian Diabetes Congress #18ADC. I have highlighted this as an issue of concern before here and here and the anecdotes of hospitalised people with type 1 make alarming reading.

Whilst there was an overwhelming acknowledgement that there is much room for improvement in this area I remain concerned about the lack of concern around how quickly people with type 1 can suffer serious consequences of too much or too little insulin. There was no differentiation between the way that insulin-dependent, non-insulin dependent but on insulin and not on insulin 'diabetes' patients were being 'managed' in the presentations made from hospitals. Whilst the data recording systems that are reviewed by a nurse educator every 3 days (!) are great to identify type 2 patients who need a treatment review because of persistently high sugars etc. It's too late if a type 1 is in DKA for a DNE educator to look at where their sugars were three days ago. I was struck by the lack of urgency in type 1-again I think this comes down to stigma about diabetes in general and a lack of understanding and appreciation that type 1s are walking a tightrope between severe hypoglycaemia and DKA every day-the state of "dangerous safety" that Banting referred to some time after he developed the 20th century wonder-'drug' insulin.

A really bright spot amongst the presentations was one by Rebecca Munt, a PHD candidate with a nursing background who also trains Diabetes Educators. Rebecca's research was on the experience of people with type 1 whilst being an inpatient. I LOVE this way of bringing the voice of people with diabetes into the healthcare discussion.

This is what Rebecca presented as what we already know (telling and a bit alarming)



What we know

- People with T1DM become expert self managers (Paterson & Thorne 2000; Thorne, Ternulf Nyhlin & Paterson 2000; Type 1 Diabetes Network 2011)
- Health professionals have a ‘poor’ knowledge of T1DM management (Smith et al 2005; Anthony 2007; Cohen et al. 2007; Maynard et al 2008; Noschese et al 2009; Fowler & Rayman 2010; Abdelkarem & El-Shareif 2013; Mabrey & Setji 2015; Shah and Rushakoff 2015)
- No guidelines or evidence to support self-management in hospital (NHMRC 2005; Craig et al 2011 ; ADS 2012; ADA 2015; NICE 2015)
- ACSQHC consumer centered care focus and patients’ experiences evidence check rapid review (Australian Commission on Safety and Quality in Health Care 2012; Harrison, Walton & Manias 2015)

Rebecca’s research involved focus groups and interviews with t1s who’d been hospitalised in the last few years and a theory on this experience was suggested and co-designed with the research participants (that’s my very rough attempt to explain constructivist grounded theory-if I’ve got it wrong I hope somebody will tell me).

What Rebecca found was:

T1DM self-management experience i
hospital model

Hospital influences on T1DM self-management	Every day influences on T1DM self-management	Internal driver of T1DM self-management
Limited health care professional (HCP) knowledge	Contextual decision making	Keeping Self Safe
Lack of trust of HCP	Asserting expertise	
Feeling judged	Maintaining control	
Limited diabetes interactions	Being vigilant	

This really resonates with my experiences in hospital and with the many stories I've heard from type 1 friends and acquaintances. We are not being difficult, we have good evidence to support the fact that HCPs in hospital settings are quite ignorant about type 1 diabetes and we need to be vigilant to keep ourselves safe. We manage our diabetes 24/7, self-management should be the default situation unless we are truly mentally incapacitated.

Some years back the British Medical Journal published a great, type 1 diabetes specific article titled, What happens when you know more than your Doctor, amongst its findings:

> *Patients who have in-depth knowledge of their condition encounter problems when their expertise is seen as inappropriate in standard healthcare interactions, and expertise taught to patients in one branch of medicine* ***can be considered non-compliant by those who are not specialists in that field.***
>
> *Although patient education can give people confidence in their own self-management skills,* ***it cannot solve the power imbalance that remains when a generalist healthcare professional, however well meaning, blocks access to medication and supplies needed to manage chronic diseases successfully.***
>
> https://bmjopen.bmj.com/content/3/11/e003583?cpetoc

This quote really sums it up for me!

PS. I was overjoyed that Rebecca's presentation was awarded the best ADEA Abstract at the 2018 Australian Diabetes Congress #18ADC. I really hope that the HCPs who need to hear this were listening!