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IDENTITY FORMATION, ONLINE RESOURCES, AND YOUNG ADULTS WITH TYPE ONE DIABETES MELLITUS

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ABSTRACT

One of the fundamental processes of transitioning from being a teenager to a young emerging adult is the construction of a gendered identity. For a young emerging adult who has been diagnosed with type one diabetes mellitus, an extra layer of complexity has been added to this task. Previous research has found there to be a paucity of information about the interactions between type one diabetes mellitus and gendered identity formation, especially in the young emerging adult population in New Zealand. This study considered how living with type one diabetes mellitus influenced a young adult's gendered identity construction, and how this identity is portrayed and shaped through the use of social networking internet sites. It also investigates what information is readily available online about type one diabetes mellitus for this population, and whether it mirrors their experiences. Interviews with six young New Zealand adults who had a diagnosis of type one diabetes mellitus were carried out, and four media articles about type one diabetes mellitus were accessed online. A grounded theory analysis was performed using a constant comparison approach. This resulted in a framework which explained how control over the chronic condition is the most important factor for the participants' identity formation, and how gender issues, support from others and being supportive of others, perceptions of others, and the restrictions type one diabetes creates feeds into this sense of control. It also explained how social networking sites, a now popular mode of internet socialising, are an important mode of socialising and accessing non-type one diabetic support for the individuals studied. If a young adult has control over their condition, they are able to confidently incorporate it into their identity and be happier and healthier as a result. Insight into how this population manages their identity construction whilst incorporating their diagnosis, and also how social networking sites are utilised by this population, has implications for the provision of care by health professionals.

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CHAPTER ONE

TYPE ONE DIABETES MELLITUS AND YOUNG EMERGING ADULTS

The literature tells us that young emerging adulthood is a time of transition, and as such it is a crucial time in the evolution of a person's gendered identity. Having a diagnosis of type one diabetes mellitus (T1DM) complicates the process of finding one's place within the social, gendered and historical context in which one exists, as it requires discipline, structure and the acknowledgement of its influence over day-to-day living for the best health outcomes. It can impact every organ in the body as well as the lower limbs and the eyes. T1DM is one of the most common chronic conditions in New Zealand's young people, and although its rate of occurrence in the New Zealand population does not appear to be high, it is in comparison with the rest of the world, and is on the increase.

In this chapter I will define T1DM and outline the impact it can have on a person's health and wellbeing. Secondly I will describe the differences between T1DM and type 2 diabetes (T2DM). Thirdly I will outline the therapeutic recommendations for controlling the condition. Next I discuss the prevalence of it in New Zealand, its impact on the New Zealand health system, and what initiatives the New Zealand Ministry of Health (NZMOH) has put in place to improve health outcomes for those diagnosed with it. Then I will look at what is required of a young emerging adult to manage their T1DM on a daily and long term basis, and the impact it can have on their families.

Type One Diabetes Mellitus Defined

A person diagnosed with insulin dependent diabetes mellitus, or T1DM as it is more commonly known, is not immediately obvious to others. T1DM is an auto-immune condition which is usually diagnosed in childhood (Kelleher, 1988), although it can develop at any stage of life (Diabetes New Zealand, 2008b). The name diabetes mellitus has Greek and Latin origins and reflects one of the most common and historically the earliest recognised symptoms, which is a frequent passing of high sugar content urine (Diabetes Forum, n.d., as cited in Tresslor, 2008).

A diagnosis of T1DM is made when a person's immune system attacks the pancreas, which is then unable to produce enough insulin naturally to convert the glucose in the body into energy (Diabetes New Zealand, 2008b). Although T1DM is not a hereditary disease, if there is a history of it in a family an individual's likelihood of developing it will increase (Diabetes New Zealand, 2008b). It is diagnosed with blood and urine tests, is not preventable, and as yet has no cure (Diabetes New Zealand, 2008b). The main symptoms of T1DM are thirst, passing a lot of urine, weight loss, tiredness and moodiness; there can also be abdominal pain, nausea, vomiting, skin infections, thrush, hunger or poor concentration (Diabetes New Zealand, 2008b). If left unattended it can cause kidney failure, eye disease, foot ulceration, a higher risk of heart disease, diabetic Ketoacidosis (a diabetic coma) and premature death (Ministry of Health, 2003). Life expectancy can be reduced in people who have T1DM by an average of up to 15-20 years, however there are many factors involved in this and as medication and knowledge improves so too does life expectancy estimations (Kay, Davies, Gamsu, & Jarman, 2009).

Confusion between Type One Diabetes Mellitus and Type Two Diabetes Mellitus

Some of the previous literature reports that people have a lack of understanding about the difference between T1DM and T2DM (Rasmussen, O'Connell, Dunning, & Cox, 2007). T2DM is the most common form of diabetes, and is classified as a lifestyle disease rather than a congenital disease like T1DM (Diabetes New Zealand, 2008a). The factors that predispose a person towards a diagnosis of T2DM are being overweight, not exercising, having a blood relative that has it, or being Maori, Polynesian or Asian in ethnicity (Diabetes New Zealand, 2008a). The misunderstanding between the two types of diabetes can lead to a person with T1DM feeling misjudged and frustrated, as T2DM carries connotations that a person has not been socially responsible and neglected their health to the extent that they get a chronic condition (Rasmussen, et al., 2007).

Therapeutic Recommendations

Lifelong daily management of T1DM is necessary, this consists of injections of insulin from one to four times a day depending on an individual's needs, and balancing the body's food requirements with its blood sugar levels (Kelleher, 1988). Blood sugar levels can be tested after administering quick acting insulin, before and after meals, and also before going to bed at night; Diabetes New Zealand (2008a) suggests people write down their levels in a daily diary so that they can track trends in their blood sugar levels over time, and see clearly any irregularities which need further exploration. Along with food and insulin there are a number of other factors which can affect blood sugar levels, some of these are physical and mental illness specifically stress, alcohol and other medications (Wilson, 2002). In conjunction with this, regular exercise and medical check-ups every three months are recommended to maintain a healthy balance (Diabetes New Zealand, 2008a). In the short term T1DM is not life-threatening or painful and generally people feel well; non-adherence with medical recommendations is common, and for these reasons the regular medical check-ups are important to pick up on any early warning signs that the balance has been upset (McKay, Glasgow, Feil, Boles, & Barrera Jr, 2002).

Incidence and Government Approach

Approximately 15,000 New Zealanders have T1DM. This is 10% of the total diabetic population which includes type 1, type 2 and gestational diabetes (Diabetes New Zealand, 2008b). Prevalence is lower in Maori and Pacific Island peoples than in Pakeha (Ministry of Health, 2003), and worldwide the incidence was reported as being more common in Caucasian populations than in other populations (Onkamo, Vaananen, Karnoven, & Tuomilehto, 1999).

The burden of T1DM on the New Zealand health system is relatively low, with 2540 people aged 0-24 counted with it at the 2001 census out of a total population of 3,737,277 people (Wu, et al., 2005); however quality of life for the individual is impacted more and long-term complications are greater than they are for any other type of diabetes (Ministry of Health, 2003). The NZMOH reported in 2003 that New

Zealand's incidence was very high in comparison with the rest of the world, and for reasons that were not defined it was described as being on the increase by an average of 3% per year both in New Zealand and internationally. In 1999 after reviewing data published on incidence trends of T1DM, Onkamo et al. reported that a study in Auckland, New Zealand revealed the incidence of T1DM in children aged fourteen and younger as being the eighth highest rate of growth at 6.4% per year, out of thirty seven populations spread across twenty seven countries. The data selected for analysis was published between 1960 and 1996, with the Auckland data from a study which lasted ten years beginning in 1977. They suggest the worldwide growth may be due to the populations who are genetically pre-disposed to having a diagnosis of T1DM increasing, but are unable to confirm this hypothesis and suggest a study spanning more than one generation needs to be conducted to explore this sufficiently.

If people with T1DM follow therapeutic recommendations (which were outlined earlier in this chapter), their incidence of illness and hospitalisation can be significantly reduced, however not everyone does this. There are a number of possible reasons for this including a lack of support or education, the cost of doctor's visits and medication, difficulty accessing services, a lack of culturally appropriate services (Ministry of Health, 2003) or the desire to have a life free from the constraints of T1DM. The NZMOH (2004) believe that intervention is the key to lowering poor health outcomes for people with T1DM. They are trying to break down the barriers to accessing primary health care for people with diabetes by creating initiatives such as the Get Checked Programme and the Care Plus Programme; these both aim to provide lower cost easily accessible treatment, and help patients to set educated and realistic self directed and self managed health goals (Ministry of Health, 2004). The Get Checked Program aims for all New Zealanders with Diabetes to have a free annual check-up with their nurse and doctor where they will have all risk-factors for diabetes checked, and ensure follow-up specialist care is arranged if needed (Ministry of Health, 2010). It also collects anonymous data for a national diabetes register, which is used to plan improvements to primary healthcare services specific to the different regions of the country (Ministry of Health, 2010). Care Plus is a programme which targets people with high health needs due to having chronic health conditions; its success has been in

the fact that it provides subsidised medical check-ups and is health focused not disease focused (Ministry of Health, 2004). Its approach is holistic, being inclusive of all aspects of an individual patient's life which relate back to their health, rather than being illness specific (Ministry of Health, 2004). Patients with T1DM do not want to all be treated the same, but rather as with a Care Plus approach, would like health care professionals to treat them as individuals who are in unique situations which need an individualised treatment approach (Wilson, 2002).

Young Emerging Adults and Management in Daily Life

Emerging adulthood is a concept which was developed by Arnett (2000) to describe people in their late teenage and young adult years, when socially expected adult commitments such as leaving home, becoming financially independent, marriage, and developing a long-term career path can be postponed and with self-reflection alternatives can be explored (Erikson, 1968; Luyckx, et al., 2008), such as higher education, travel, or different career options. The relevance of this concept to the current research is that along with the above opportunities, emerging adulthood is a time when the dependent identity created as part of the childhood family unit is examined and re-fashioned according to life experiences to create an independent identity (Arnett, 2000), and for a person with T1DM this means taking full responsibility for monitoring symptoms and managing the treatment of the illness, whilst establishing an independent life.

Research shows evidence that young adults want to be more autonomous and re-define their identity as they seek to break their dependence on the family unit, so they can make new friends and acquaintances as they transition from school to higher education or to new work places; however this autonomy can be threatened by overprotective parents, a regimented medical routine, and the close monitoring of medical professionals (Sparud-Lundin, Ohrn, & Danielson, 2009; Wilson, 2002). Balfe (2007) found in a study of 17 British university students narratives that students endeavour to maintain multiple identities, one which complies with stereotypical student norms, but also another to satisfy what is expected of a responsible health conscious person. Their research found that the context a person was in and the social

practices their peers engaged in dictated what identity they displayed, for example when publicly socialising the research participants did not take their testing kits with them to avoid the medicalisation of their identity in a context where they desired to be seen as having a 'normal' identity.

If a person with T1DM maintains their daily management plan it does not mean their lives and those around them will not be impacted by it, unfortunately the restrictions on people with T1DM make it difficult for them to engage in some of the usual activities of their peer group (for example, unstructured meals, taking part in unplanned sporting activities, and drinking alcohol) without careful planning, and accepting there could be negative health consequences (Wilson, 2002). Alcohol consumption is perceived to be an important social activity for a young adult and for their ability to create and maintain friendships and a normative identity, but it does place T1DM control at risk (Balfe, 2007). The NZMOH (2003) stresses the essential need for all people with T1DM to be well educated about their condition so they can make informed choices about their health, and this education needs to continue throughout their lives and not just be focused on the time when they are first diagnosed. There is a trend for individuals to become frustrated and angry as they move from childhood to adolescence at the restrictions placed on them by T1DM which set them apart from their peers (Tilden, Charman, Sharples, & Fosbury, 2005). Balfe's (2007) research found that although a person may go through transitions which could be classed as deviant and irresponsible in many cases over time a more mature, educated identity would come to the fore, and with it the selection of a more supportive social circle and better control of T1DM.

Family Impact

As will be discussed further in the following chapter, family support is very important for an individual's physiological and psychological wellbeing when they have a chronic condition such as T1DM. Parents, especially mothers, are often very actively involved in the care of their children's T1DM before they reach adulthood, and may help guide them through the transition to being a more independent person in charge of their own healthcare (Cameron, Young, & Wiebe, 2007). Caring for a child with T1DM can

be a demanding and time consuming pastime, with medical appointments, administering and understanding medication requirements, and special diets to consider (Rasmussen, Dunning, Cox, & O'Connell, 2008). Some parents may need help in accepting their 'different' child and feelings of loss, as may siblings who could get less focused attention due to not needing specialised care (Rasmussen, et al., 2008). Ructions can occur between the parents of a child with T1DM due to extra stress and one parent being overly involved, often the mother, in comparison to the other (Rasmussen, et al., 2008).

Mothers who are overly anxious about their children's T1DM care hamper the transition to independence, and can lead to resentment in their child, poorer management skills and poorer blood sugar control with increased diabetic symptoms as a consequence in the young adult (Cameron, et al., 2007). A person can also become overly sensitive to any statements about their condition and perceive all talk about it by others to be criticism (Paterson, Thorne, Crawford, & Tarko, 1999). It is not clear whether any rebellion or conflict experienced by adolescents and young adults against their parents impedes the development of a secure identity (Tilden, et al., 2005), however the more communication between parents and children, and the more autonomy allowed when appropriate, the more likely guilt feelings for the child and anxiety and stress for the parents will be reduced (KyngÅs, 2004).

Summary

T1DM is a serious chronic condition for young emerging adults and their families to have to deal with. The ramifications of neglecting it are great. It is one of the most common chronic conditions in young people in New Zealand, and it is on the increase. Despite often being classed as the same thing, T2DM is quite different from T1DM in that it is not a congenital disease, and it carries negative connotations which can be transferred onto people with T1DM. The NZMOH is trying to make health care for all diabetics more accessible, both culturally and financially, with the Care Plus and Get Checked programmes. These programmes use holistic approaches to treatment, which enable the individual patient to play an active part in the planning of their treatment plan. This is ideal in the emerging stage of a young adult's life as they

transition to taking over the full care of their condition, and move into a more independent and exploratory phase of life.

CHAPTER TWO

YOUNG ADULTS LIVING WITH TYPE ONE DIABETES MELLITUS

In this chapter I firstly discuss the important process of identity formation in young adults and how having a chronic illness such as T1DM can impact on that identity formation. As I will show, previous literature indicates the influence that T1DM can have over a person's life is significant, and the young adult stage of life is one where adherence to medical recommendations can be low due to a person's desire for a 'normal' life in line with their peers. Secondly I will discuss gendered identity, and how in western society there are expected gender norms for males and females. These expected norms do not always make the need for constant health monitoring and medical attention easy to accept or openly acknowledge, and previous research has found the stresses this can have on an individual may lead to declines in mental and physical health. Thirdly I will highlight the importance of support for people who have T1DM, be this from friends, family, school networks, healthcare providers or technology. I will then discuss the growing use of Social Networking Sites (SNSs) by young adults, and how these may aid in identity formation, sociability, and in finding new support networks. Throughout the chapter I will consider the previous research, especially in the areas that have not yet had adequate attention in the literature, in respect to the current research project and the aims of the research.

Chronic Illness and Identity

Adolescence and early adulthood is a time of identity construction; constructing an identity which makes sense and fits with an individual's ideals is an extremely important process at this time of life (Erikson, 1959, as cited in Subrahmanyam & Greenfield, 2008), but it also continues throughout our lives. Erikson (1968) stated that given a time of life where responsibilities and obligations are low, we can experiment with our identity, emerging adulthood can be such a time. An identity is socially constructed from the interaction of thoughts, feelings and the physical appearance of a person, and the reaction of others to the portrayal of those thoughts, feelings and appearance; as new experiences and interactions occur an identity

evolves (Tilden, et al., 2005; Zhao, Grasmuck, & Martin, 2008). "Identities define, locate, characterize, categorize, and differentiate self from others" (Charmaz, 1995, p. 268). As people get older they adopt values and belief systems which they can apply to certain social settings as appropriate, and also these values and beliefs help an individual to place themselves within their social context (Wilson, 2002).

Although a young emerging adult is able to take their time establishing their identity, a chronic illness adds an extra layer of complexity to the construction of that identity, and the management of a chronic illness such as T1DM could create an internal struggle between the different areas in their lives (Luyckx, et al., 2008; Mey, 2007). It is a disease which threatens independence due to the required vigilance of blood sugar levels which can be affected by food, exercise, alcohol, medication, illness and even stress, and this has a knock-on effect on all aspects of life (Wilson, 2002). An internal struggle could be triggered as this time of exploration and non-commitment stands in contrast to the nature of T1DM, which requires at least a semi-structured life for health to be maintained. How people with a diagnosis of T1DM perceive their condition influences how they see themselves, and in the same way how they see themselves influences their perception of their condition (Kelleher, 1988). For example, research has shown that many teenagers and young adults with T1DM would rather be part of a social peer group, complying to its norms at the exclusion of their chronic illness from their public persona (KyngÅs, 2004; KyngÅs, Kroll, & Duffy, 2000); in addition they would rather neglect their daily medical needs than be healthy, different, and friendless (Williams, 2000). However despite the fact that these young adults have made a choice to neglect their medical needs, it does not prevent them being anxious about the long term effects of their actions (Balfe, 2007).

People diagnosed with T1DM have different ways of incorporating it into their lives, Luyckx, et al. (2008) hypothesised that some reluctantly accepted diabetes dominance over their lives but others avoided the issue altogether. They also found that these two groups had more diabetes related problems and a higher rate of depression than those who were able to construct a strong identity which incorporated their illness. As mentioned in the first chapter, some people with chronic illnesses maintain multiple

identities, and only show what they perceive to be the appropriate identity for a particular situation (Balfe, 2007; Kelleher, 1988; Wilson, 2002).

Research shows that people with T1DM often struggle to be responsible about their diabetes (Balfe, 2007). As research participants this population often choose not to mention T1DM, or it does not dominate their stories, as they do not want their illness to define them and would rather be seen as 'normal', autonomous, and valued despite their illness (Balfe, 2007; Tilden, et al., 2005; Wilson, 2002). To feel valued despite a chronic illness it is important that those around a person with T1DM, for example parents, do not place too much focus on the condition but rather help them see their life holistically, made up of many different elements, such as sports, hobbies, friends and interests that they enjoy (Wilson, 2002). In a single case study of a British woman by Tilden, et al. (2005) it was found that for a person with T1DM to be in control of their illness they needed to discard the notion that they are the object of the disease and differentiate themselves from it. This study also found that there was a paucity of psychological research into the dynamic between T1DM and identity.

Along with the pressure to have a perceived 'normal' identity, Balfe (2007) and Rasmussen et al. (2007) talk about how people with T1DM can feel there is an expectation from society, family and from themselves to have a good diabetic identity, this is being responsible, living healthily, and following recommended medical practices; to actively maintain health is to be a responsible member of society (Lyons & Chamberlain, 2006). Constant monitoring by family or friends for signs of illness or non-compliant behaviour can create pressure and this is counter-productive to healthy outcomes (Tilden, et al., 2005) as stress has been linked with poor glycaemic control, and depression has been linked with an elevated risk of diabetic complications (Enzlin, Mathieu, & Demyttenaere, 2002).

Many participants in previous research have listed diabetes as the thing they disliked most about themselves, or talked about diabetes as a negative and embarrassing experience (Dickinson & O'Reilly, 2004; Wilson, 2002). However a person with a chronic condition can experience a transformation in their self-identity, learning to live with their condition and turn it into a positive part of their identity rather than a

negative one; it challenges them to stay healthy and make good decisions (Paterson, et al., 1999). Luyckx et al. (2008) found that if individuals with T1DM have a strong sense of who they are, they are able to develop sound strategies to integrate T1DM into their identity development, an integral part of the evolution for them from adolescence to adulthood.

In summary, young emerging adults are at a time in life where there can be many changes in their social, work and family context; their identity will continue to evolve, and how they incorporate T1DM into their lives will need to adjust with it. Society stresses the importance of healthy living, and taking full responsibility for one's healthcare could be part of the move from adolescence to young adulthood as people become more independent from their childhood home. In this stage of life socialising with peers becomes more important and this brings its own set of challenges, of fitting in and feeling accepted by one's peer group by complying with idealised gender norms. T1DM is not conducive to some young adult pastimes, and as young adolescents with chronic conditions can be very sensitive to peer group norms this can create internal conflict, stress and depression or lead to unhealthy behaviours.

Gendered Identity

Society imposes gendered norms on males and females from birth, and as people journey through their lives there is a continuing need to establish how they fit into the gender group within which they exist. Traditionally women are associated with nurturing and are expected to maintain their health and the health of their family; they are expected to be caring and giving of their time and energy whilst maintaining a physical appearance which complies with current social norms (Lyons & Chamberlain, 2006). Men are expected to be strong physically and emotionally, and in control of their bodies; they should be able to play sport, do physical work, and be independent (Lyons & Chamberlain, 2006; Williams, 2000). Aspects of gender impact on health management, and the management of health impacts on the construction of the gendered self (Williams, 2000). A person with T1DM can be at odds with their expected gendered identity, and young people are at a critical time in terms of being in control of their condition, and consequently are more likely to engage in risky

behaviour to achieve gender ideals (Williams, 2000). These risks will now be explored further.

Society's expectation that women will manage their own healthcare can lead to females feeling pressured into a situation where they cannot seek out support if they need it without feeling like a burden (Rasmussen, et al., 2008; Williams, 1999). They have been found to worry more than males about physiological ailments, and feel guilty when they are not doing all they could be to maintain their health (Williams, 2000). Females with T1DM are more likely to be unhappy with their body image than other females, and as physical attractiveness plays a role in being and feeling accepted into a social circle, many do not take their insulin or take a reduced amount of it to avoid putting on weight (Wilson, 2002). Although this goes against the social expectation of maintaining their physical wellbeing, it does help them to conform to the female gender ideal of being slim. Many research projects have found that maladaptive eating attitudes and behaviours are more common in females with T1DM than females without T1DM; these attitudes and behaviours have been found to be a precursor to eating disorders, and they also impact on glycemic control (Kichler, Foster, & Opiari-Arrigan, 2008; Schneider & Delamater, 2006). Having an eating disorder can give a sense of control over the body, and self-control is prized in western culture where there is so much temptation to eat unhealthily (Giddens, 1991). Females with T1DM may gain back the sense of control that T1DM can erode by restricting their calorie intake, and they may also feel a sense of belonging to a social circle if they comply with the aesthetic expectations of the group. This is further supported by the NZMOH (2003) making nutrition a target factor in their plan to reduce the ramifications that type 1 and type 2 diabetes can have on peoples' lives, and they advocate for diet and nutritional planning to be part of a regular diabetic check-up so as to improve insulin treatment success and adherence, and to reduce the negative effects that poor nutritional practices combined with T1DM can have on a person's body.

Despite the negative influence T1DM can have on females, Williams (2000) found in the in-depth interviews she carried out with ten males and ten females aged between

15 and 18 years who lived in and around London, that once females accepted it as a part of their lives they were able to include it into their identity permanently. This was displayed by taking their insulin in public and being happy to talk about their condition with other people. Similarly, Dickinson and O'Reilly (2004) found in their interview results from ten American adolescent female participants, that despite the fact that they had times when they wished they were free of their condition they didn't see why T1DM should be considered a major hurdle in their lives, they had found their own way to accommodate it into their identity and expressed the wish that their parents, friends, teachers and health carers just let them get on with the business of being in control of its management. Although it is difficult to say if the same positive influences would have occurred had a person not been diagnosed with T1DM, it has been found to enable people to live their lives in a different way, with different rewards and different relationships which they may not have had otherwise (Paterson, et al., 1999).

Certain social contexts are not conducive to having an illness or being health conscious, such as a boy's night out on the town drinking. Health research has found that a common male stereotype is not needing to share health concerns or to ask for help from health professionals (Addis & Mahalik, 2003; Courtenay, 2000). This contrast with females is highlighted in Williams 2000 study above, where her male participants tried to keep their condition as small a part of their lives as possible by not talking about it with friends or acquaintances, and by not taking their medication in public places. Charmaz (1995) found that it took a diabetic crisis, such as losing a foot, before male participants studied would alter their lifestyle to accommodate their diabetes, and Courtenay (2000) found that men were more likely to perceive themselves as invulnerable to ill health and generally less knowledgeable or interested in health than women, and this reinforces the societal norm of what masculinity should be. An example from Charmaz (1995) research is "A man with diabetes could not manage both his wheelchair and a tray in the cafeteria. Because he could not bring himself to ask his co-workers for help, he skipped lunch and risked a coma" (P. 284). If a man embraces the main stereotypes of masculinity, a growing body of literature suggests he will have poorer health behaviours and health outcomes overall (Courtenay, 2000).

Illness can cause identity dilemmas for both males and females, and males especially are given less leeway with their expected gendered behaviour (Courtenay, 2000) and this can result in recurrent and chronic dilemmas as their place in the masculine hierarchy is threatened (Charmaz, 1995). Identity dilemmas occur when valued attributes such as physical functions and the ability to fulfil social roles are compromised (Charmaz, 1995). An example of this is that Williams (2000) found her male participants endeavoured to keep their T1DM in check with mental strength and exercise rather than with medication or diet. The mothers of males who refused to be interviewed for this study were interviewed instead, and they reported their sons had not managed to gain control of their T1DM, as a result they were angry and made little or no effort to improve their health as they expected to die early regardless of their efforts. A social constructionist view is that females and males adopt their views on femininity and masculinity from the culture they are raised in and that they are an active agent in that process, so that when an individual is reacting to a health issue they are reacting in a way that is in line with their gender beliefs; if they choose not to conform to stereotypical gender norms they can be punished and devalued by their gender peers (Courtenay, 2000). Males can also devalue themselves when they are unable to perform the risky behaviours that get associated with masculinity, such as fighting or drinking heavily, and if a male cannot act in a socially expected way then he is behaving in what could be seen as a more feminine role (Courtenay, 2000).

Feminine and masculine attitudes and approaches to T1DM can be very different. However there are inconsistencies in the diabetes literature about how different genders cope with a chronic illness like T1DM. A growing body of health literature has shown that “being a woman may, in fact, be the strongest predictor of health-promoting behaviour”, and to be male is to generally have poorer health practices (Courtenay, 2000, p. 4). Williams (1999, 2000) and Charmaz (1995) found women adjust better than males to the diagnosis of T1DM and could integrate it into their identity more successfully, this was illustrated by the females studied taking their injections in public places and the males waiting until they were in private before they had theirs. Williams (2000) and Enzlin, et al. (2002) found their male participants aimed to make their illness the smallest part of their lives and identity as possible. A

similar amount of research, which has been conducted in different parts of the world and across various stages of life supports the opposite view, that males adapted better than females with fewer hospitalisations (Dickinson & O'Reilly, 2004), less depression (Enzlin, et al., 2002; Kay, et al., 2009), guilt (Rasmussen, et al., 2008), or anxiety (Kay, et al., 2009). Three of these studies gathered data with interviews and the fourth used psychological self-rating questionnaires.

In summary, previous research highlights the differences in gendered approaches to healthcare; this is in part a result of society's expected gender norms, and also a result of an individual wanting to portray the correct gendered identity. However stereotypical maleness does not comply with society's expectation of being a healthy responsible citizen, and maybe this could help account for the inconsistencies found in the literature about a male or a female's adaptation to T1DM being part of their gendered identity. This would suggest more gender specific research needs to be carried out to explore what part gender plays in the successful inclusion of T1DM into a person's identity, and where the risk factors are so that support services can be targeted to those that need them most in keeping with the NZMOH's diabetic health plan. Also this would enable an individual's support networks to be utilised to their full potential.

Support

Relationships with peers are important for social adjustment and for helping people to feel good about themselves, and support networks are very important for emerging adults with T1DM. KyngÅs, et al. (2000) found adolescents with T1DM are more socially dependant than adolescents without a chronic condition. For a person to have a large accepting social network of friends is of the greatest benefit, and if some of these friends share the experience of a chronic illness an individual is more likely to have good emotional well-being and adjust psychologically to their condition (KyngÅs, 2004; Rasmussen, et al., 2007; Wilson, 2002). It is also good for friends, teachers and work colleagues to know if someone has T1DM, and to have some knowledge of what to do if difficulties arise (Ministry of Health, 2003).

Perceived social stigma can be one of the barriers affecting compliance in people with T1DM (Odegard & Capoccia, 2007). A person may try to hide their illness, and this can lead to risky behaviour so that they can conform to the identity that they think fits the situation they are in (Balfe, 2007), in the case of a person with T1DM this could mean not taking their insulin when they are out in public, and consuming food or drink high in sugar. Kyngäs, et al. (2000), Wilson (2002) and Williams (2000) report that having a chronic illness like T1DM can be viewed as a weakness by a person's peers, especially for males, which is limiting and isolating, and it can be damaging to one's sense of self, however Sparud-Lundin, Ohrn, and Danielson (2009) found that although young emerging adults with T1DM may assume other people will judge them to be weak due to their illness this was actually not always the case, and with experience they would find that their identity was not threatened by T1DM and on the whole other people could be accepting of their situation.

As discussed in the previous chapter, T1DM has a considerable impact on the lives of diagnosed individuals and their families (Luyckx, et al., 2008; Ministry of Health, 2003), and people with a diagnosis of T1DM can feel guilty as a result of the impact (Rasmussen, et al., 2008). A New Zealand study where 59 adolescent participants and 47 mothers completed questionnaires, found that overprotective mothering resulted in lower metabolic and psychological control of T1DM and a reluctance by the adolescent to take over full control of their condition (Cameron, et al., 2007). Multiple studies have found that parents who are able to be supportive and express interest in all aspects of an adolescents' life rather than just focusing the illness, are found to be a crucial part of support networks, along with healthcare providers, school networks, and technology (Kyngäs, 2004).

Healthcare providers are also an important part of a young adult's support network. Kyngäs (2004) found in a qualitative research study where 40 Finnish adolescents with chronic diseases were interviewed about their support networks, that health care professionals, especially nurses, who could be empathetic to an adolescent in regards to the difficulties that T1DM presents in their life are seen as allies and a strong support contact, rather than only as a source of medical information and a supervisor

of their condition. Rasmussen, et al. (2007) did a grounded theory research study with 20 Australian women aged between 20 and 36 years and found similar results to William's (1999) grounded theory study discussed above, in that if health care providers were detached and illness-focused in their approach to patients, they were more likely to hide non-adherence or any difficulties they were having with their treatment. They felt pressure to be in control and not utilise ongoing support from their health professionals. William's (1999) study found that the participants had long periods of non-adherence, but that they could not explain this behaviour when asked about it.

School networks are another good source of support for people with T1DM. If teachers, school nurses and fellow students can be accepting of a person's chronic condition in a way that does not hold them apart, but rather is inclusive, it aids in the individual's psychological adjustment to their condition (KyngÄs, 2004). Also technology is another medium where support can now be found, and if necessary the support seeking can be anonymous. The next section of this chapter will explain in detail how the internet has developed and evolved into being a support network for people with chronic conditions and identity issues.

Social Networking Sites

The internet is an interactive medium, which allows access to endless information, and instant communication. It has been integrated into developed countries business, home, and social life. A survey carried out in 2007 by researchers at the Auckland University of Technology found that 78% of New Zealanders use the internet, 77% check their email daily, and 71% say it is an important source of information (Nagpal, 2008). In contrast to face-to-face encounters the internet removes the physical body from interactions online and with it non-verbal features of communication, such as body language or physical attractiveness (Bargh & McKenna, 2004; Garza, 2002), and can enable an identity to be constructed to suit the social environment.

Social networking sites (SNSs) are a popular social environment on the internet which adolescents and young adults can use to try out and form new identities in. SNSs are:

“web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system” (Boyd & Ellison, 2008, p. 211).

SNSs enable a person to socialise with friends, make new friends, set up business connections and tout political agendas (Boyd, 2011). To attract friends a SNS user sets up a profile, an integral part of a SNS (Boyd, 2011), to represent themselves. The profile can include basic information, such as a photo, age, religious and political beliefs, relationship status and interests; it is set in a historical and social context and can be subject to fashionable ideals and interests (Boyd, 2011). Access to a person’s profile can be restricted to only the ‘friends’ a user chooses to create a link to, or can be open to any user of the SNS. Boyd and Ellison (2008) point out these contacts may not be ‘friends’ in the same sense as they would be offline as the connection can be much more casual; Papacharissi (2011) states ‘friends’ are made in part to help authenticate a user’s identity and create a sense of connectedness with peers and extended family.

Boyd (2011) conducted a series of predominantly ethnographic research around different aspects of SNS use with American populations, and this collection of research has enabled her to discover that people make conscious choices about whether to mix their different offline social circles in their online social environment. She discovered that it was dependent on how people wanted to be seen by the online ‘Friends’ that they make; intersecting social circles can become difficult if a SNS user wants to express themselves in a manner which may not be acceptable to some of their associates. A SNS user with T1DM for example may choose not to include a parent or a member of a diabetes social circle in order to maintain their removal from that part of their life, and avoid perceived disapproval if they advertise that they have ‘broken the rules’ in regards to their condition. In a special section Boyd wrote with Ellison in 2008 they state that the ability to make causal claims about SNS use and its importance could not yet be made as there was a significant lack of large scale experimental or longitudinal studies performed in this area, especially outside of the United States of

America. They call for more research with richer in-depth data to clarify who is using SNSs and for what purpose.

In a literature review Bargh and McKenna (2004) cite two separate quantitative studies which explored the success of friendships formed over the internet. The first study was performed in 1995 by American Communications researchers Parks and Floyd, and was one of the original studies on relationship formation on the internet; it administered a questionnaire to 176 people who were part of an internet bulletin board discussion newsgroup. The typical respondent was a 32 year old single male, and two thirds of them reported developing a personal relationship with another user of the newsgroup. The second study was a psychological survey carried out by McKenna and Bargh in 1998 with nearly 600 randomly selected participants, who again were participants in popular newsgroups. Their correlational findings were followed up as part of the same study with three laboratory experiments with American male and female first year psychology students. Both studies found that online relationships had a similar success rate to those formed offline, and one of the reasons for this was because people felt they could express their true selves more successfully over the internet, focusing on the aspects of themselves that they held as most important. The result of their review shows that psychological well-being for the users of the internet and SNSs depend largely on the reasons for use but if they are motivated by a desire to create social contacts, rather than to push a political agenda for example, they will be reasonably successful. Bargh and McKenna (2004) felt that there needed to be more research conducted with special populations in regards to the success and usefulness of socialising over the internet.

An advantage of SNSs is that users can experiment with how they want to present themselves in a forum that allows for constant revision of their portrayed identity (Livingstone, 2008). Livingstone (2008) performed sixteen open-ended discussions with male and female teenagers of differing ethnicities in greater London, and found that the younger adolescents did indeed repeatedly re-create their online identity in different and detailed ways to express changing trends and interests, whereas older

adolescents were more inclined to give accurate information and have an online identity similar to their offline one.

There is a school of thought which states the internet and SNSs do not provide any benefits and in fact may stunt development, isolate and expose their users to predators and bullies (Bargh & McKenna, 2004; Livingstone, 2008). However a greater number of studies have found that SNSs contribute towards developmental needs and identity formation in young people as they allow identity development and social interaction with different communities, and provide support socially and medically in an environment that can predominantly be controlled (KyngÅs, 2004; Subrahmanyam & Greenfield, 2008; Zhao, et al., 2008), although a SNS user cannot control what other users post about them (Boyd, 2011). This could be valuable for people with T1DM as research has found people with chronic conditions can feel more vulnerable in new situations, and feel more pressure to conform with peer norms (Balfe, 2007). In addition to this research has found that new mediums of socialising can be successfully integrated into a person's routines, and contribute and expand their sociability rather than detract from it (Papacharissi, 2011).

SNSs are an anonymous environment in which people can communicate comfortably with others and if wished, withhold their true identity. In previous research Dickinson and O'Reilly (2004) found their adolescent female participants' second biggest worry was whether to tell others about their T1DM, also they were frustrated with constantly being questioned about their condition; furthermore Rasmussen et al. (2007) found the issue of disclosure caused years of internal conflict. In the SNS setting information about T1DM can easily be reserved, along with any other information that a user does not want to share with others (Papacharissi, 2011), although it may not be the best alternative both for a person's physical and mental health. Alternatively a person may also reveal more of their true selves, or their hoped-for selves, than they might in a face-to-face encounter; "the Internet plays an important role in identity empowerment" (Zhao, et al., 2008, p. 1818).

The type of profile generated by a SNS user ties in with who they want to make connections with (Boyd & Ellison, 2008). Some users only connect with people they

already know offline, and so their profile is a truthful description of who they are, others are looking for new friends or relationships and may tailor their profile describing of who they would like to be, or alternatively they may create a fictional identity (Boyd & Ellison, 2008). Users may also seek an online group with similar issues as themselves, as they may be in need support not being provided for by friends or family (Rasmussen, et al., 2007; Subrahmanyam & Greenfield, 2008). This online support can lead to improved coping with an illness (KyngÄs, 2004). Online support groups for chronic illness have been studied often, they can fill a gap that is not available offline, and are important for an individual's sense of identity; "because of the anxiety and uncertainty they are feeling, patients are highly motivated by social comparison needs to seek out others with the same illness, but prefer to do this online ... because of the anonymity afforded by Internet groups" (Bargh & McKenna, 2004, p. 583). There is less risk with disclosure online, an ability to transcend location issues, and greater access to diverse sources of support and health information (Sparud-Lundin, et al., 2009; Wright & Bell, 2003). Also research has found that talking with unknown peers online can help with perceived social rejection (Subrahmanyam & Greenfield, 2008). Interestingly Bargh and McKenna (2004) found that offline diabetes support can be just as beneficial as online support groups, however the more support someone with T1DM has the better their adherence to a healthy diabetic regime (McKay, et al., 2002).

In summary SNS use is growing fast, especially amongst the younger New Zealand population. This use may be of benefit to young adults with a diagnosis of T1DM for experimenting with their identity in an environment which can mostly be controlled, SNSs are also an additional support network from their offline support. However a search on PSYCHinfo revealed there is still not a lot of research being done on SNSs use, their benefits or their pitfalls amongst any populations (Baker & White, 2010; Beer, 2008; Boyd & Ellison, 2008). This research project will attempt to explore who is using SNSs, for what purpose, and how the users position themselves in online diabetic discussions. It will look specifically at web pages which provide a forum for people with T1DM to discuss relevant issues and build a picture of who they are in an online

setting. It is hoped the information found may be useful for support websites and healthcare workers.

Research Objectives and Aims

Gendered identity construction in young emerging adults is a complex and constantly evolving process, and in the twenty first century the use of online forums for support and as a means to establish one's identity is becoming increasingly important. The ability to form a secure and independent identity in such a transitional phase of life is understood to be an essential factor influencing the maintenance of good health and life satisfaction. Societal norms expect individuals to be rational and responsible members of society by striving for good physical and mental health and to be compliant with expected gender norms, but they fail to take into account the emergent context in which young adults exist along with the complicating implications of a chronic illness such as T1DM. KyngÅs, et al. (2000) and Balfe (2007) found that more research was needed on the impact a chronic condition can have on an individual's life, and what having one means for a person, and Tilden, et al. (2005) felt not enough psychological research had been performed exploring identity formation for diabetics, and more research could assist in identifying ways to increase health and wellbeing in this population. Although there have been many research studies done on the subject of the effects of T1DM on identity in adolescents in the last ten years, a very limited amount focused on the emerging adult phase of life, or was specific to New Zealand populations. Also the literature accessed as part of the investigation into this thesis' aims has not given a definitive answer to which gender copes better with a diagnosis of T1DM, but does indicate that there are strengths and weaknesses on both sides; this indicates that further study into this area could give some clarity.

Overall my research objectives are:

1. To discover how living with T1DM influences a New Zealand male or female young emerging adult's sense of identity,

2. Look at how a gendered identity is portrayed and shaped through the use of SNSs, and explore the material that is available online in New Zealand regarding diabetes for young adults who might be seeking information
3. By investigating individual experiences the aim is to broaden the psychological knowledge base of this research study's specific population, and also how SNSs are being used and by whom.

CHAPTER THREE

METHODOLOGY

This research explored what having a diagnosis of T1DM meant for a male or female young emerging adult's identity formation, and how this gendered identity is portrayed and shaped through the use of SNSs, and how T1DM is portrayed through online texts. A qualitative research design was used in order to obtain and analyse the data. This chapter outlines the rationale for the utilization of a social constructionist qualitative approach to examine the above aim along with describing the data generation and analysis methods that were used. Secondly it will discuss the participant recruitment process, including the difficulties encountered and the participants' demographic information. Thirdly it will describe the method which was employed to analyse the semi-structured interview data and online media accounts regarding T1DM, and the subsequent themes that emerged. Finally it will consider the role of the researcher in the data analysis.

Social Constructionism

Social constructionism is a paradigm that moves away from the more traditional positivist perspective, which does not account for the role of an individual's social and historical context in regards to how they approach their reality, but rather sees human nature as fixed, waiting to be discovered and generalised across populations by psychologists (Moghaddam, 2005). Social constructionism allows research to be done on a diverse range of topics in a diverse range of settings (Charmaz, 2003), as it aims to uncover how personal knowledge and meaning about the world a person lives in, the experiences they have, and about who they are, are constructed by individuals (Lyons & Chamberlain, 2006). Personal knowledge is not something which has to follow the same rules for everyone, there is no one truth, but rather it is something people uncover as they interact with each other (Gergen, 1985), and it continues to evolve as an individual moves through their life (Moghaddam, 2005). Social constructionism assumes there are many possible definitions for an experience, and these definitions are all valid within their own cultural and historical context (Burr, 2003). It also

assumes that the meanings individuals construct on their own, within groups, or between individuals and the wider community, can be analysed to understand how they perceive the world (Charmaz, 2003). Thus every person's understanding around a topic will be individual, and not necessarily a commonly held perception of reality.

Social constructionism is based on three main points. Firstly, that all psychological phenomena (thinking and decision making for example) are learnt about through the interactions of individuals with others (Moghaddam, 2005). In this research how participants interact with others online and offline enables us to learn about how they create meanings around their identity and their chronic condition. The second point is that all psychological writing is located in a specific historical context and based on the normative rules and values held at that point in time, also it draws on current psychological theories and concepts whether intentionally or not (Moghaddam, 2005). This research project will be influenced by my current beliefs about health and identity, and the psychological teachings that I have been exposed to. Thirdly all social realities are based on the culture that surrounds them (Moghaddam, 2005). The current research will be based in a European New Zealand (Pakeha) cultural setting.

Burr (2003) describes social constructionism as lending itself more to qualitative methods of research rather than quantitative methods; the latter are more in line with traditional cause and effect research which aim to scientifically deduce an outcome to be reported. Although social constructionism does not class quantitative methods of research as invalid, it does seek to reveal the process of meaning making rather than just reporting the end result.

Qualitative Approach

People change over time as their experiences change, making it difficult to truly understand their separate worlds by measuring them en-masse (Langdrige & Hagger-Johnson, 2009). Mey (2007) describes qualitative research as a holistic approach which examines individual cases, so as to develop a deeper understanding and perception of another's reality at a particular point in time, in order to describe and interpret it. It enables an understanding of issues by eliciting the meaning associated

with them from the individuals who are currently living with them, contributing towards a greater picture about a phenomenon (Wiseman, 1999). Due to the desire to acquire in-depth data, a qualitative approach was the most appropriate for this study.

Qualitative data is richly descriptive and should be presented in a way which allows for the reader to make up their own mind about the findings, rather than as a fixed truth; and these findings may vary significantly across participants depending on their individualised reality (Merriam, 2002a; Wilson, 2002). Also the findings of qualitative data should be presented as the understandings of the researcher involved, the same data could in turn have been presented differently by another research that lives in a different social or historical context (Merriam, 2002a).

Grounded Theory

Grounded theory was developed in the 1960s by sociologists Glaser and Strauss, and is used across many social science disciplines (Pidgeon & Henwood, 1997). The term grounded theory describes “the systematic analysis of unstructured qualitative data” (Pidgeon & Henwood, 1997, p. 254). Its basic approach allows themes to emerge naturally from data rather than being forced upon data (Charmaz, 2003). It “involves seeking social processes within a given phenomenon about which little is known” (Rasmussen, et al., 2007, p. 301), and explores the understanding and meaning of experiences from individuals (Langdrige & Hagger-Johnson, 2009). Although grounded theory is a well established and highly structured methodology it has evolved and developed different approaches over time, starting with Glaser and Strauss’s initial model which Glaser felt focused on the data more than the evolved Strauss and Corbin version which highlights phenomenology more (Chamberlain, Stephens, & Lyons, 1997). Charmaz (2006) contends that a number of scholars have since moved beyond both of these versions of grounded theory to one less focused on positivism, but which still use the basic components of grounded theory such as coding, memo-writing and constant comparison. This research study works more in line with Charmaz (Chamberlain, et al., 1997) who describes the findings of grounded theory as the social construction by the researcher of the social constructions of the research participants displayed in the data gathered.

Grounded theory's basic analysis method is constant comparative analysis, where the researcher constantly compares the evolving codes and categories back with the original data in order to lead to a central framework (Tuettemann, 2003). This process involves various stages of coding (which will be outlined further) and memo writing, which records the similarities or differences a researcher may see between the different sets of data whilst they are going through the analysis process (Merriam, 2002b). Along with this the researcher immerses themselves in the data as soon as they begin collecting it, and this enables the analysis findings to help narrow the focus of the data collection still to be done (Langdrige & Hagger-Johnson, 2009).

One of the strengths of grounded theory is that the codes and categories developed from the data are grounded in the current realities of the participants who take part in the research, or the authors of extant texts (text not generated from interviews), so it stays true to their perspectives and contexts, exploring 'what is' rather than getting distorted by previous theories and research findings or the researchers pre-conceptions (Tuettemann, 2003). This is achieved in part by the interview questions used being general and open rather than leading to a specific hypothesis (Chamberlain, et al., 1997). What a researcher sees in their data is in part a reflection of the experiences and perspectives the researcher has had previously in their lives, it is important that they recognise that their opinions are only one opinion amongst many and should not overrule the data collected from participants (Charmaz, 2006).

The Current Study

Research Process and Changes in Design

This study was altered throughout the course of the research process due to participant recruitment difficulties. This research initially started with a design in which it was hoped participants could be recruited via an online Facebook webpage for New Zealand diabetics, which has 59 members. Approval to do this was gained from the Massey University ethics committee and subsequently the administrator of the webpage, but there were no responses to the invitation to partake in the research. Then the Diabetes Trust in Manawatu placed an advertisement in their youth

magazine but this method did not produce any participant interviews either. Recruitment was then attempted via the Hastings Regional Hospital's Diabetes Outpatient Clinic, this clinic provides education and healthcare to patients with type 1 and type 2 diabetes, and this is where the participants in the study have been recruited from.

Interviews

The semi-structured interview schedule was compiled during a review of previous literature on the subject of T1DM and identity formation in young adults and SNS use (see Appendix A). Semi-structured interviews were chosen as they help to prevent a participant from being dominated by the researchers own assumptions, and allows them to give their own views and understandings on the subject of the research (Mey, 2007).

Before the start of each interview, I offered the participant another copy of the information sheet (see Appendix B) to read and made sure the participant understood their rights, what was required of them, what the interviews would be used for, and that they would be audio-taped. Participants were given assurances of confidentiality and anonymity, and asked if they had any further questions. Once both parties were satisfied, the participant was asked to complete an informed consent form (see Appendix C), where they were also given the option to receive a summary of the results once the research had been completed.

The interviews, which lasted on average 30 minutes, were recorded on an Olympus digital voice recorder, and then backed up onto my laptop computer. I used open-ended questions to encourage the participants to tell their own stories, and I sought further clarification of issues raised as necessary. A few general questions were asked initially to help put the participant at ease and gain some more background information. They were then asked about their use of SNSs and how T1DM featured in this use, whether it was a part of their online profile or whether it purposefully was not, and if they had found support online that they did not have offline. Questions

were asked about their experience of T1DM and how it featured in their lives and as part of their gendered identity.

The interviews were conducted in a venue of the participants' choosing; two were in cafes, one at the participant's house, and two in libraries. The interviews were all conducted in English and provided rich data that reflected each participant's personal experiences and opinions.

One of the participants was unable to meet up for an interview and so replied to the interview questions via email. In this case and one other who had earlier done a face-to-face interview, further questions were asked via email to clarify the initial answers given. In the first instance the data gained was not as rich and in-depth as the interview data. This may have been because the salient points could not be followed up on at the time they were written. In the second instance the answers were actually more detailed than the interview data. It shows that different people are comfortable giving interview answers in different forums. The quotes used in this thesis from the participant emails have had the spelling errors corrected.

The interviews were transcribed by the researcher verbatim using a simple notation guide (see Appendix D), where significant pauses, overlapping speech and any speech which was inaudible was recorded. Notes were taken at the end of each interview to jog my memory about the context of the interview and demeanour of the participant so that it could be taken into account when analysing and presenting the data.

Participants

The target group for this research was young emerging adults living in New Zealand, aged between 16 and 25 who had a diagnosis of T1DM, and who used social networking sites. The age range was chosen due to it being a time of increasing independence and opportunity for change.

The sample was comprised of six participants (see Table 1), two males and four females aged 16 to 21 years with the mean age of 18 and a half, who consented to participate in the study. They had lived with T1DM for between 1 to 20 years, 8 years

being the mean amount. They all identified as being New Zealand Europeans/Pakeha, and one also identified as being Maori and another as also Southeast Asian.

Table 1					
<i>Participant Demographics</i>					
Pseudonym	Age	Ethnicity	Occupation	Number of Years with T1DM	Forum
Amanda	18	NZ European/Pakeha	Tertiary Student	7 years	Interview & Email
Jenny	18	NZ European/Pakeha	School Student	5 years	Interview
Katie	21	NZ European/Pakeha	Tertiary Student	2 years	Interview
Sarah	17	NZ European/Pakeha	School Student	1 year	Email
Simon	16	NZ Maori NZ European/Pakeha	School Student	13 years	Interview
Walter	21	NZ European/Pakeha Southeast Asian Other European	Tertiary Student	19 years	Interview

Due to the method of recruitment being via a medical provider who has to maintain patient confidentiality, no information was available on those people who chose not to participate in the study, although the data analysed is the realities of people who are living with a diagnosis of T1DM.

Procedure

An advertisement to recruit participants (see Appendix E) and an information sheet containing the broad aims of the study were sent to all patients registered with the Hawkes Bay Regional Hospital's diabetes outpatient clinic who met the research criteria. These patients all live in the Hawkes Bay area. The clinic did two mail outs, 76 letters were sent out the first time and 61 were sent out the second time.

Respondents were invited to express their interest to the researcher via email, and this showed they had access to the internet and so could be accessing SNSs. The researcher sent them back a quick demographic questionnaire (see Appendix F), and when this was returned an interview was arranged. Respondents were also invited to

ask any questions about the study that they may have, and were told they could withdraw from the study any time with no penalty.

Ethical Considerations

Informed Consent

The participants were sent an information sheet initially with the advertisement about the study which outlined: their rights as a participant (e.g., their ability to withdraw from the study, to ask questions, or to have someone else present); brief details about the research aims; what was required of them (including the time the interview was likely to take); the assurance of confidentiality and anonymity and how their data would be kept secure; what the interviews would be used for; and the fact that they would be audio taped. The participants were offered the information sheet again prior to signing the informed consent form in case they wanted to read it again or ask questions about it. Once the interviews had been transcribed they were sent to the participant, so they could read them and amend or exclude any of their data to be used for the study. They were asked to return the transcripts, if they were changed, with a signed transcript release form (see Appendix G) so the analysis could begin.

Confidentiality/Anonymity

Confidentiality was maintained in several ways. Firstly, pseudonyms were used for the participants and friends or family mentioned by them when the interview data was transcribed and the research was written up. Secondly, access to the participants' data was restricted to myself and my thesis supervisor. Thirdly, computer files and emails from participants were password protected so as to prevent unauthorised entry. Finally, the audio recordings were destroyed on thesis completion.

Ethics Committee Approval

The first research design was approved by The Massey University Ethics Committee. Once the research design needed to be changed a new ethics application was submitted to The Health and Disability Commission's Ethics Committee in Wellington and the project was reviewed and approved by them (see Appendix H). The research

was also approved by the research committee at the Hastings Regional Hospital (see Appendix H).

The Online Media Texts

Inherent in doing a qualitative study is the analysis of text, this text may be from interviews, but it can also be from other sources which the researcher has had no part in producing, this is called extant text (Charmaz, 2006). These texts can be from a variety of sources and been produced for a variety of reasons, they can be the primary source of data for a research study or be complementary to interview data, used to support and expand upon the interview data as was the case in this research (Charmaz, 2006). Similar to interview data, extant texts are constructed within a certain social context, and should be treated as a snapshot of the author's assumptions and intended audience at that point in time, rather than something which is neutral and can be generalised to other contexts (Charmaz, 2006; Sandlin, 2002).

For the extant texts I selected three online magazine based texts from diabetic publications and a TV3 Campbell Live news item which discussed living life with T1DM, in order to flesh out the interview data collected. The news item was transcribed in the same way the interviews were. These texts were all accessible online via the *Diabetes Youth Auckland (DYA) Press* an online magazine published by Diabetes Youth Auckland, and via the New Zealand Diabetic Society's magazine *Diabetes*. The specific articles that were selected consisted of:

- A three page article entitled "Family Support for League Star 'Living with Diabetes'" (Diabetes, Winter 2008).
- A one page column entitled "Having a Life with Diabetes: Diabetes and Alcohol" (DYA Press, March 2010, p. 13).
- A one page column entitled "Having a Life with Diabetes: Off the rails" (DYA Press, June 2010, p. 13).

The online TV3 Campbell Live news item is available on tv3.co.nz to view 'On Demand'.

The specific news item was:

- “Type One Diabetes: An Unavoidable Curse” (Campbell Live, 19 November 2010).

A copy of all the media articles can be found in Appendix I.

The two articles written by Nic Reade for the *DYA (Diabetes Youth Auckland) Press* talk about a teenager’s journey through to adulthood, and use some of her experiences as examples. They discuss what a challenge it is to keep good control over T1DM, whilst being a normal emerging adult who should be able to engage in normal age related activities and not stand out as different from the rest of their peer group.

The third magazine article written by Lance McEldowney for *Diabetes* magazine, is about 37 year old Steve Renouf who is an Australian rugby league star. He was diagnosed with T1DM at the age of 22, and three of his five children have also been diagnosed with T1DM. This article illustrates how a good attitude towards T1DM and good support from family and friends can make a big difference to a person’s ability to integrate T1DM into their lives.

The television article was a human interest piece on TV3’s Campbell Live program. The interviewer Lachlan Forsyth spoke with three people who have a diagnosis of T1DM: Max Rogers who is a teenager, and at the time of the interview had only had the diagnosis for approximately three weeks; Alfrey Bloom who is a twenty-something young adult; and Win Johnston who was diagnosed at seven and was 82 years of age at the time of the interview. The interviews give a good cross section of people with T1DM in terms of age and years of experience with T1DM.

Analysis

The data for the study included the patients’ initial screening questionnaire, their semi-structured interviews, the researcher’s notes and memo writing, and the internet media texts. The screening questionnaire provided information on participants’ age, ethnicity, gender, what year they were diagnosed with T1DM, and what SNSs they used. The semi-structured interviews took place between July 2010 and December 2010. The internet media articles were accessed from an online internet search, to see

what information was available to New Zealand young adults that focused on T1DM, and whether the articles would tell a similar story to the participants. From the search, three magazine articles and a television human interest article were selected.

In keeping with the grounded theory method the analysis of data began as soon as possible and occurred simultaneously with the data collection. The interview transcripts and the media articles were examined line-by-line in the first instance and code words were identified, these notes were then categorised to create a focused list of open codes (Glaser, 1978, as cited in Charmaz, 2006). The third phase of coding, axial coding (Strauss & Corbin, 1990), looked at the connections that could be made between the initial codes and grouped them to develop several main codes. Finally selective coding was done to identify core themes, which could account for variations in participants' experiences, and which led to the development of a framework of understanding around these experiences (Strauss & Corbin, 1990).

Researcher Reflexivity

As stated earlier, it is important to acknowledge a researcher's role in the research process, analyses and results (Charmaz, 2006). My participation in each interview could have influence the social context of the interview, and there are several factors which should be considered: the age difference between myself and the participants, the age gap ranges from 13 years to 18 years; the fact that I am a female may have influenced how participants responded, the females talked more on the whole so maybe felt they had more in common with me than the males did; my demeanour and the way I asked the questions; the possible unconscious affirmation of a respondent's answer which complies with the approved societal norm of being healthy and the absence of this affirmation in response to an answer which does not comply, may have influenced how the participants responded to further interview questions; or because the participants may have placed me in an assumed position of superiority as the 'researcher' and a person who is enrolled in postgraduate study. Also as I have never had a chronic illness it is possible that I am not aware enough of the experience to ask pertinent questions in a manner which will elicit informative responses from this group of people.

I do have some background knowledge of medical professionals' expectations of their patients with T1DM and the struggles these patients may have, due to being employed in medical centres for almost four years. This may have influenced what questions I asked, how I asked them, and the responses I gave. This experience may have also coloured my analysis of the data and led me to be more attentive to the data which complied with pre-conceived ideas about the research aims than data that did not.

In the next chapter I will discuss the findings of my research.

CHAPTER FOUR

RESULTS

Having a diagnosis of T1DM is a unique context for young emerging adults to exist in. This population are at a stage in life where there are many opportunities available, and each of these opportunities, for education, employment, or socialising, can lead them to a different direction in life, and factor into their identity construction in different ways. The aim of this research was to explore how young adults discuss their lives and their identities within the context of living with T1DM, and the role that SNSs may have played. This research study found that several factors play a part in the management of the diabetic self and the construction of an individualised gendered identity, with control being the core category, and these findings will be discussed in further detail in this chapter and illustrated with quotes from the participants.

Also as part of this research four media articles written by or about people who have T1DM were analysed, to see whether there were common themes with the participants' experiences. In this chapter the findings from the analysis of these articles will illustrate further that control over T1DM is enhanced by a good support system of friends, family and medical providers. Added to this, if a person can learn how to deal with others perceptions and the restrictions that T1DM places on their life, they can integrate the demands of their condition into their daily practices and so into their identity.

Data Analysis

The results of the ground theory constant comparative coding approach are the categories which emerged from the participants' interview data. These interconnected categories form the basis for a grounded theory framework which describes how the participants construct their individual gendered identity whilst allowing for their chronic condition, and how the use of SNSs features in this process. In the first phase of analysis a total of 107 code words were identified; these were such things as *spontaneity*, *study*, and *future*, which could be grouped together around a particular concept in the data, in this case *restrictions*. During this second phase of

coding 30 open codes were identified. These were identified by the questioning and comparing of the code words with one another. The next phase, axial coding, pulled the data together and made connections between the open codes to develop several main categories. In this study six axial codes were identified, these were *control*, *support*, *perceptions of others*, *gender issues*, *restrictions*, and *SNS use*. The final phase was selective coding, this was where a core category was established and the remaining categories could be related back to the core category in a framework which described the key findings of the research. The core category in this research was *control*, and the other categories apart from *SNS use* were modified by a person's control, as in turn control was modified by the other categories, as can be seen in Figure 1.

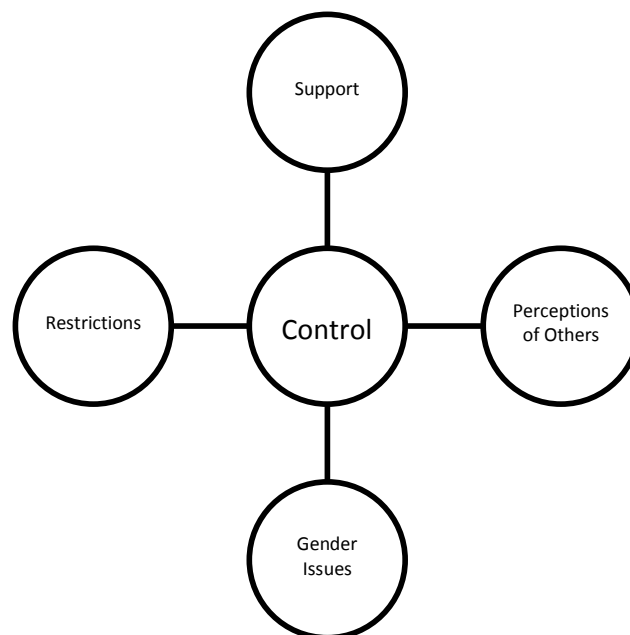


Figure 1: A framework of Gendered Identity Construction in Young Emerging Adults with Type One Diabetes Mellitus

As will be explained further *SNS use* remained a separate category from the others as the participants in this research did not directly use the SNSs to help them create a gendered identity which incorporated T1DM. However they did use SNSs as an online environment where they could engage with others as a 'normal' young adult, rather than one where they were defined by their illness.

In addition to the interview data, four articles were downloaded from the internet and were analysed as part of this research project to assess what information was available to young adults on the internet, and how it related to their individual experiences. They consisted of one television article and three magazine articles. This analysis was conducted in the same way as the interview participant analysis, using the grounded theory constant comparison coding technique to identify initially 115 code words. In the second phase these code words were grouped into 15 open codes. From there the selective coding process identified three categories which were also in line with the categories identified in the participant interviews; these were *control*, *support*, and *restrictions*, with *control* being the core category again. SNS use was not specifically discussed, but there was reference made to a blog site which could be used in a similar way to a SNS. There were no categories revealed in the analysis of the media texts which were not found in the participant interviews analysis.

Control

Having control over T1DM emerged as the core category in this study. This was very important to all the participants, and all were adamant that they were in control of their condition and of their treatment regime. They did not want their lives to be defined by T1DM, or for other people to focus on it when interacting with them. With this control came the ability to integrate T1DM into their identity; they saw themselves as someone who happened to have a chronic condition rather than being an extension of that condition:

Katie: "... and I'm in control with what I want done with it now, happy with that and it's just moved into my lifestyle it's not changed anything that I do."

Jenny: "I'm in control."

Walter: "It's just like anything, it's just part of who I am."

Amanda: "Well it sucks, but it's just something that you do and it's just a way of life now ... that it works around me."

As part of this control there was a strength displayed in the participants acknowledging that they had not always been in control, and given certain circumstances the female participants conceded they could lose some of that control again:

Katie: "I think so yeah depending on where you are, like in stages, like the stages of your disease, um cause I was under control for awhile and then all of a sudden things went downhill and I just got this anger back all of a sudden and yeah it's taken me three months to get in control again and come to terms with my new regime and new Insulin and everything like that."

However the male participants did not think this would happen, and in fact Walter stressed that he had no health issues or difficulty with his diabetes:

Simon: "...but it's probably straight forward now."

Walter: "Nah, nah, I think I could maintain the control."

Most of the participants had experienced a debilitating health issue as a consequence of their T1DM not being well managed, such as migraines or diabetic ketoacidosis, which had been a catalyst in realising they needed to gain control over their T1DM or their condition could deteriorate and take over their lives:

Katie: "Yeah I actually made myself really sick. I wouldn't take it [insulin], I didn't want to jab myself, I didn't want to take medication."

Simon: "Um well I've been to hospital couple of times and I developed some, I don't know what it is, what it's called, it's a long word ... yeah um for not taking, like taking care of it so it was like, it just started to develop, and I've like started taking control of it."

Walter: "I had a period through um from when I think I was 13 to 17 I had a lot of migraines which were triggered by the low blood sugars, they were really bad."

As with the participants, the articles written for the *DYA Press* illustrated that people go through different stages with T1DM as they move through life, and the stage

highlighted as being particularly neglectful of T1DM in the articles was from the ages of about 19 to 25. Examples were given stating the author did not attend any diabetes related doctor's appointments for two years, did not regularly test blood sugar levels, and used unconventional methods to control blood sugars when drinking alcohol, like off-setting blood sugar levels with chocolate biscuits. These examples were further supported by the author stating that other's she had talked to who were diagnosed with T1DM and who were now in their 20s and 30s, also went through this non-adherence phase at a similar age as they wanted to:

“not stand out, they wanted a spontaneous life, they wanted rid of their chronic condition.”

The *Off the Rails* article also talked about regaining control of T1DM after experiencing the consequences of neglect, and having insight into what the future held for the health of those that did not change their approach to T1DM. It described a healthier life where T1DM was controlled, and a happier life where it was integrated into a person's identity.

Three of the female participants could attribute some of the mastering of their condition to seeing the effects of it on older people who may not have looked after their health as well as they could have. For example Amanda's grandfather had very badly controlled T2DM:

Amanda: “seeing the effects of the disease on someone you love is very hard and knowing that it is almost certain this is what is going to happen to me, brings the reality back to me.”

Sarah: “I do often see in the paper or whatever that older people with diabetes have their legs etc removed and it kinda shocks me and it makes me try and control my sugars better.”

Katie: “Yip having nursed people that don't look after themselves completely freaked me out, like amputees and people with gangrene.”

Inspiration for another of the female participants to maintain her health was drawn from her grandfather's ability to control his T2DM:

Jenny: "cause he he's had um triple bypasses and stuff and he's had like heaps of knee operations and, and through all that he's still been able to keep good control so ... yeah cause um when I was um going through like the rough patches and stuff he'd talk to me and just say that it does get better and pretty much yeah, just kept him at the back of my mind

Furthermore all participants except two, one of whom rated her family first and another who said everything else came before her condition, could see that their health had to come first, because if they were not healthy all other areas of their lives would suffer:

Walter: "Nah, that is my life so if I'm not, if I don't look after my diabetes I don't do too well."

Katie: "Unfortunately [T1DM comes first], and I think it always will be, which I'm happy, more than happy to oblige to so. Yep, 'cause if I'm not well I can't, I don't focus, I don't you know work like I should so."

Simon: "oh it's, at the moment it's like number one, but like couple of months ago for two years it was like oh nah just I don't really care."

Sarah: "No health comes first."

To be in control the participants made sure they were organised in regards to their T1DM. This included forward planning for medication requirements and meals. In addition when they were going out for the evening with friends, or were playing sports, there was usually someone there who knew about their condition, and knew what to do in an emergency:

Sarah: "... and it gives me much more organisations skills eg when I'm leaving the house I have to make sure I take insulin, blood tester etc."

Jenny: "cause if I go out and stuff I just always have to have that with, like my medication stuff with me and I just have a handbag."

Amanda: "When I'm getting ready with friends every time I remind them that if I do collapse or pass out to call a ambulance straight away and tell the ambulance person I am a type 1 diabetic on insulin."

Walter: "I always have um food and insulin in the car. I have um, in all my sports I got someone I have someone who knows what to do [in a medical emergency]."

As with the interview participants, the TV3 news article described having to be organised in order to keep the control over T1DM, and this was illustrated by two of the people that were interviewed:

"Basically wherever I go I have to take insulin, and I have to take jellybeans, and I take my test kit."

"I'll carry like some lollies or something to boost my blood sugars up if I go low."

All of the participants stated that a positive effect of living with T1DM was that they were now more aware of their bodies and of their nutritional needs, and as a result were healthier than they would have been had they not been diagnosed with the condition:

Simon: "and just like make sure that you can feel it and um you can manage it from that um feeling just go do something about it."

Sarah: "I guess it makes me much more aware of my body."

One of the male participants felt that his family were also healthier as a result of his diagnosis:

Walter: "I guess it's taught me to have more awareness about nutrition, what food I'm eating, what exercise I'm doing ... but at the same time they've [family] had to learn more about other things, like nutrition and stuff like that."

The *Diabetes* magazine article described how Steve Renouf ,the Australian rugby league player, was told by his rugby league doctor that he could still play professional league and control his T1DM, providing he approached his medical condition with the right attitude:

“It was a personal attitude thing. I could let it beat me ... or get on top of it and keep playing. I took up the latter ... it’s something (diabetes) you can live with.”

The article described how he managed to have a successful career and keep control of his condition through a managed diet, adhering to his recommended treatment regime, and keeping T1DM management as a priority, but not letting it take over his life.

One aspect which was discussed in the *Off the Rails* article which only one of the interview participants discussed directly was taking control of T1DM in order to be able to have children, or for the benefit of existing children. It would not have been discussed by the interview participants as there was no indication that they had reached a point in their lives where this was something they needed to consider, however Amanda did state she would never consider having children as T1DM would present too many difficulties for the pregnancy, and her children could inherit health issues which she did not want to be responsible for imposing on them.

The two articles written for the *DYA Press* were written from the perspective of someone who has control over their T1DM, and was able to impart some of the knowledge gleaned from their own experience to others. The author describes young adults who used to exclude T1DM from their lives, but who no longer do, as “naughty teens” in a tongue in cheek manner. It reads as a slap on the wrist statement which the author made in a tone which indicates she knows better.

The participants’ ability to control their T1DM was described as very important to their lives. For the females it was a state of being which could change given particular circumstances, but the males felt that now they had control they would not lose it. As stated previously, obtaining this control was attributed to seeing the effects T1DM

could have on the human body over time, or having personal experience of those effects.

Support

The *DYA Press* articles stated that a young adult's ability to incorporate T1DM into their identity successfully is aided by positive support from peers, medical providers and parents. On the whole the participants said they had supportive families, and were appreciative of this. They realised that to maintain their control they would need help at times from their family or from medical professionals. They did however strongly stress their ability to be independent from their families in terms of their treatment regime. This was not because they did not appreciate the support of their families, and in fact in times of illness or a medication change utilised their family support network more than normal, but rather they knew what they were doing in regards to their treatment and desired the recognition that they were more than capable of managing on their own:

Jenny: "So I've had to tell her [mum] like to back off a little bit, just I like to do it myself, like if I'm sick and stuff and I'm not feeling too well yeah my mum helps me, but other than that I pretty much do it myself."

Walter: "My family know about it better than anyone so generally I can just rely on them if I need anything."

Sarah: "My mother knows the basics but often forgets but she doesn't have much to do with the handling of my diabetes it's something I do alone."

As with family support, participants were grateful for the availability of medical support if they felt they needed it. However the support was received on their terms, they did not want it thrust upon them:

Amanda: "but I like to keep things like for me doing it because I know how like everything been affected like if I've got a really high level someone else might say that "oh something's wrong", but I can track back and think "oh no it's like

that because I had an ice-cream or because I ate my meal late” or things like that.”

Jenny: “yep, I think it’s good like not having them like in your face all the time and stuff it’s just good to know they’re there if you need them.”

Walter: “Yep the GP is good, he knows what he’s doing, I’ll go see him to him to get my prescriptions, but um, well I’m pretty sure he’d be able to offer me help if I needed it but I don’t.”

The TV3 news article was able to give insight into how medical support has improved over the course of time for people with T1DM by interviewing a person in their eighties. This insight was not given by the research participants as they were all young adults who live in an age of increased technology and medical knowledge. Seventy years ago the only way to judge the levels of blood sugar was by looking at the colour of one’s urine. The author of the *DYA Press* articles also talks about the changes in technology, although she was only diagnosed 15 years ago. Nowadays people are given blood sugar test kits which are small enough to be concealed in a handbag. An example of the change in medical support was given by the elderly lady interviewed for the TV3 article:

“You see you’ve probably heard about hypos, well the sugar drops so low, well they didn’t even tell us what that meant and the first hypo I ever had was when I, the day I graduated as a nurse and I collapsed in the ward, they carted me down to A & E in Wellington and said ‘Well what have we got here?’ and I said ‘you tell me’.”

In contrast with this, the author of the *Off the rails* article starts with a tribute to her medical specialist who has supported her and educated her through her journey with T1DM thus far, and who has been realistic, honest and openly discussed the ups and downs a teenager or young adult goes through with their condition.

Another positive experience of medical support was shown by another person interviewed for the TV3 article. The Dafne course offered by Waitamata District Health

Board was discussed and credited with helping her gain control over her condition. The Dafne course teaches people to count the carbohydrates in their diet and adjust their insulin dose to offset those carbohydrates. The news report described Alfrey as a person who did not think she would live much past 30 as she was constantly ill because of her T1DM. One of the interview participants, Amanda, had the same grim outlook on her future. She perceived T1DM as an early death sentence preceded by years of impaired function. Amanda has not yet been offered or sought out the support Alfrey experienced through the Dafne course, and so has not found the hope that Alfrey is described as having since she completed the course. Unfortunately the news report did not go on to tell viewers how they could get information about the Dafne course if they wanted to know more.

The participants felt that lived experience counted for a lot more than knowledge learnt for a medical qualification, so in this regard the support health providers could offer to them was viewed as limited:

Simon: "there's one guy there [at the diabetes clinic], that I don't know if he's there anymore, he actually had it, so yeah, but yeah it's the same, if they don't have it they don't know what it feels like. It's just like, yeah just they gotta, that, that's their job, it's you know listen and don't have to do anything about it if you don't want to."

Walter: "Um, professionals can know a lot, but um in general I think the experience is more relevant."

Katie: "and it agitates me more when they won't listen to what I have to say, like people think that young people with diabetes don't know anything, but they actually know a lot more than some doctors ... yeah through living with it, and reading up about it and things like that."

Steve in the *Diabetes* magazine article described diabetes companies as trying to provide products for their target population which they perceive as practical, but they miss the mark because they do not have the lived experience to really know what is useful for a person with T1DM. This is the same opinion that the interview participants

expressed above. The *Diabetes* magazine writes that as yet the diabetes companies have been unable to bridge the gap that remains between medical knowledge and practical lived knowledge. The subjects of the article, Steve and his wife, had begun developing consumable products for people living with diabetes as they felt they had a better idea of what would be useful for this population.

Only Amanda and Walter talked directly about their friends being part of their support networks for their T1DM, although all the participants stated that their good friends knew about their condition:

Amanda: "Some of them [friends] find this quite frightening and become too protective when I'm out and it starts to get annoying with them looking after me all the time watching everything I do. Others can think I'm joking and not take it seriously which can be a bit worrying but I just hope they remember what I told them! When other people tell me what to do like tell me I should have some lollies or not drink that really frustrates me as they don't know how it works and I am more than capable of controlling it myself."

Walter: "...and with my touch and league and gym my flatmates there he's pretty clued up with it."

The *Diabetes and Alcohol* article discusses the advantages of having a best friend on nights out who knows what to do in an emergency, although it does recommend having more than one friend well-informed when drinking. A person with low blood sugars displays similar symptoms to someone who is intoxicated. In a group it is more likely that someone will be able to recognise the symptoms and take precautionary measures early enough, rather than relying on one person to be in a situation to help.

To have the shared experience of diabetes with another family member was very important for two of the female participants (their relatives had T2DM), as they were able to be supportive of each other when they hit rough patches, and serve as inspiration for each other in maintaining control:

Jenny: “yeah cause um when I was um going through like the rough patches and stuff he’d talk to me and just say that it does get better and pretty much yeah, just kept him at the back of my mind.”

Amanda: “seeing him suffer and knowing that I am the only one in the family that can truly relate to him and understand what he is going through gives us a special bond.”

This shared experience is also discussed in the *Diabetes* magazine article amongst the Renouf family. An illustration of how important this can be was when Steve and his wife were able to recognise a symptom of T1DM, extreme thirst, in their son and take him to hospital where he was diagnosed with the condition and started on insulin straight away. They were also able to recognise early signs in two of their other sons before they developed into emergency situations. The children of this family had been fortunate in that they have seen their father live a happy successful life despite his diagnosis, and each in succession had been able to draw on the experience and knowledgeable support of the previously diagnosed family members.

Several of the participants had gone on a diabetes camp in their first years of diagnosis, and one had been to a diabetes conference, and found them comfortable, normalising environments to be in:

Amanda: “like cause they all understood everything and you kind of didn’t have to explain it you just had fun and understood each other.”

Walter: “I think it’s quite good, it’s quite cool um knowing that everyone else there is the same, um not the same, um has the same issues, but I don’t have a problem.”

SNSs can also provide access to online support, whether the support is specific to T1DM or whether it is just a method of socialising with peers. Jenny was the only participant who had linked up to diabetes specific SNSs, and did so particularly to re-connect with people she had met through the diabetes camps:

Jenny: “Mmm, I have on Facebook, I haven’t, I’ve looked for one I’ve found I think two or three but yeah, I’ve added them. Yeah, cause um I’ve met a couple of other diabetics and stuff through like um rafting trips and stuff and it’s good to see like some of them are on that page as well, so now I can talk to them again and so, see how things are with them. Yeah cause some of them go through the same things so, it’s good to see you’re not like alone really.”

Interestingly the majority of participants had not looked for T1DM related SNS pages and were not really interested in doing so, however all of them felt it could be a useful forum to be a part of, specifically in the first year of diagnosis when support from peers in the same situation would be extremely helpful; one participant suggested they could also be a helpful support network for caregivers:

Sarah: “maybe, to like talk to other diabetics, share stories etc”

Walter: “yeah I think so, um yeah people who are diagnosed older, having any trouble, or parents or caregivers who don’t understand.”

Katie: “yep I do. I wouldn’t personally use one now but I know that when I first got diagnosed and I went on a diabetes camp with a whole heap of other kids that had it to that really helped. Yep, I reckon for about the first year it’s all you need is support.”

One of the female participants who was still at school was part of a support group with other diabetic students. As she was in her last year of school she was looked up to for support from the younger students:

Jenny: “Um like because I’m older than them I see a lot of things in them that I’ve been through because at school we like all meet together I think once or twice a term, and like we just talk about what’s happening and they usually ask me a lot of things because I’m older than them and I’ve been through a lot of things they’re going through.”

There seemed to be some pride in being able to be supportive for others with T1DM, and for another female participant a career goal was to be able to help others with

T1DM. She felt she would be able to do this well due to her experience with the condition, and would still be young enough for newly diagnosed teenagers and young adults to relate to:

Katie: “well it’s something I’m gonna you know push when I, when I graduate I really want to do something about it ... and be there ‘cause you know I’ll still, I’ll be 23 when I graduate so I’m still you know young adult, so I can get out there helping them more.”

Two of the media articles give reference to other supportive resources which the readers could utilise. They are both books written by people are living with T1DM and so could have some good insights for their target readers, which are young adults, or the parents of young emerging adults. They are credited with describing how to live through the teenage to young adult years in as safe a way as possible, without having to isolate oneself away from ones peer group.

The knowledge that there are different sources of support available for the participants in this study was reassuring to them, especially the support of those who had personal experience of T1DM or another chronic illness; however they did fiercely maintain that they could manage their condition on a daily basis without it. The *Diabetes* magazine article talked about how supportive family, friends and work colleagues could aid success in all areas of life including health. This article recommended that young adults educate the people who live and work with them about T1DM so they can help if there is a medical emergency.

It was interesting to find that the participants had not utilised the support available on the internet, and yet indicated they felt it could be helpful for newly diagnosed people and their families. It is possible the participants felt that by using the internet support they were admitting they could benefit for the help others could provide in an online setting, which could contradict their firm stance of independent control over their condition.

Perceptions of Others

Respondents did not mind being called a 'diabetic' as having T1DM was part of who they were, and they were certainly not ashamed of their condition. When asked if they would hide their condition from others in social situations the majority of the participants said they would not, however they did not advertise it either. As stated previously they did not want to be defined by T1DM, and they did not see it as a relevant piece of information when making new friends or acquaintances, either online or offline. For some of the participants, the experience of others' perceptions had at times been a negative one. Two females had become very guarded about where they took their medication and who they told about their condition; one of the male participants had a very gendered approach to negative feedback:

Amanda: "and the lady goes "Oh yes the sick one, so that's not very nice to be known as the sick girl."

Katie: "Yeah I'm quite, I dunno, I guess people tend to look at you differently. You're very wary of what other people are looking at as well. If they use something else like a pen-jabber or you know a needle-injector or some of the things people have got are incredible."

Simon: "um, if they act like, some people at school make fun of it, they're like you can just, cause when they're outside of their group that do it, you can just like, like have a go at them. Cause um I'm bigger than most people that do it so, yeah."

The participants agreed in general there is a lot of confusion between T1DM and T2DM, even amongst those who have diabetes:

Katie: "Um, quite a few people say um you know, type, type two's the worst and you know cause you don't know you have it, and in a way I can kinda see where they're coming from but, their disease progresses a lot faster ... and um the other one's skinny people have type one, fat people have type two, not true."

Jenny: “but he’s type 2 so and I’m type 1 so, but he was real upset he thought he’d given it to me, I said ‘no’.”

Amanda: “My Granddad has diabetes. He originally had type 2 but did not look after it and it turned into type 1.”

T2DM cannot turn into T1DM, however if a person’s T2DM gets out of control they may need to start taking insulin, the medication for T1DM. The participants felt some of this confusion was born of the fact that T2DM gets a lot of focus in school health education and in the media, and there is no education about T1DM. The female participants talked about the misconception many people have that to be diagnosed with any type of diabetes means a person has a bad diet and is overweight.

Jenny: “yeah um like I’ve, at school and stuff like people that I talk to but not often enough for them to know that I have diabetes um if they find out or if I tell them or I mention something about it they’re like ‘oh you have diabetes but you’re not fat’ it’s just it’s the different types and I have to explain that to them.”

Amanda: “Like at high school and stuff and we’ll be learning about health they’re like ‘don’t eat that don’t eat sugar or you’ll get diabetes’ and you can kind of see everyone and they’re kind of looking over at me and it’s like no there’s two types but people don’t say that there’s two types, and they always like kind of give you this look as if to say ‘eww you yuck person you did that to yourself’.”

Simon: “There’s um TV always talks about type two and saying diabetes, and it’s just like that’s confusing really.”

People who do not live with T1DM can be very ignorant in terms of how they relate to those who have the chronic condition of T1DM, and also in terms of separating out T1DM from T2DM. T2DM has been given a lot of attention in the media as it has been related to the ‘obesity epidemic’, which is a high focus health issue in New Zealand at present. But also general health has become a moral issue as we are taught the cost of

a person's ill-health falls on the shoulders of tax payers. Amanda's experience illustrates society's judgement of other people's health issues, and especially of illnesses which have lifestyle related causes, as T2DM has. As stated above, popular media and health educators do not help the lack of knowledge about T1DM by focusing on T2DM and not explaining the differences between the different types of diabetes. As part of creating an identity the participants showed it is important that one feels understood and accepted as normal, rather than being branded as sick or as having deviant behaviour.

Gender Issues

The research explored the role of gender in the participant's identity. It was hoped there would be more male participants, as men's experiences of identity formation and of T1DM are not often researched, however this was unable to be achieved due to the afore mentioned recruitment difficulties.

The female participants' varied in their responses regarding gender and adaptation to having a diagnosis of T1DM:

Katie: "I dunno, I've seen, I've talked to quite a few young people with it and it kinda depends on the person as well as to I reckon how it affects them, how they let it affect them."

Sarah: "I believe men take it harder than woman, I think woman can adjust easier."

When the female participants were asked about any specific gendered effects of T1DM they had experienced or noticed in others their answers complied with gender stereotypes, in that males would be affected in sports and females would be affected in appearance and diet:

Jenny: "Probably women I'd say because um I've noticed that with women like the injections, cause they can leave bruises and your stomach and stuff ... and like you can get like little bumps and that and I'd say more for women because

like it's more of the physical appearance thing really ... you'd feel more self conscious about it as in men wouldn't really care as much I don't think."

Amanda: "Maybe different 'cause men do more activities and women watch what they eat more or something I'm not sure ... and you wouldn't picture a girl to kinda be like 'I need food now, give it to me' ... and also with like syringes and like injecting yourself, it's not very ladylike thing to do."

Katie: "I think the only negative thing is if you're dressed up nicely in a dress and you're going out and you need to inject yourself you've got to go away and do that."

The male participants did not think there were gender differences in adaptation, and Walter only raised pregnancy as a gender issue:

Simon: "It doesn't, there's not really a difference, it's just like, they usually just accept it, yeah, can't change it."

Walter: "I couldn't imagine a difference, perhaps for pregnancy might have some issues, but that's all I can think about."

The female participant's answers complied with gendered norms in terms of being concerned about physical appearance and having a healthy diet, whilst the male participants were not concerned about these specific issues or any which could have been classified as masculine in nature. In the participant's opinion, incorporating T1DM into an identity was a unique experience for each person, and the level of personal strength to overcome gendered challenges was more relevant to their success than their gender.

Restrictions

T1DM requires a person to juggle their responsibilities for their condition with everyday life. On the whole the participants in this research did not want their T1DM to define them, or hold them back from achieving goals they had set themselves:

Simon: “you know, um doesn’t stop me from doing anything, cause yeah I um ride, I ride motorbikes, I drive, and um I, I’m in first level Hockey at school.”

Walter: “[in regards to playing sport] Nah, no um I just have to make sure I have something, some sort of energy drink or, I go through a lot of Powerade.”

Amanda: “Well it sucks [having to be organised], but it’s just something that you do and it’s just a way of life now.”

All three of the TV3 report’s interviewees were involved in sports, and they all described having to be organised and being careful to make sure that they did not put their health at risk by overdoing exercise. They talked about needing to be aware of the signals their bodies gave them, and having to calculate how vigorous the sport would be against how much insulin they had and what they had eaten that day. As previously discussed, for the oldest subject of the TV3 report things had changed quite a lot in regards to T1DM management and restrictions as time had passed. As a result it has taken a lot longer for her to learn what her body’s signals meant, whereas the two other people interviewed for the report and this research study’s interview participants have been diagnosed in a time of far advanced technology.

There was one participant who had concluded she would not be able to achieve all she would like to in her life. Amanda believed that she would not live as long as a person without T1DM, and that once she was in her thirties she would start to have serious health issues due to her condition:

Amanda: “what the thing to do is go to school grow up get married and have children, not having this plan set out makes me think what am I going to do in the future and while all my friends are off living their lives with their children I could quite possibly be living in a wheel chair.”

None of the participants felt they had been disadvantaged in terms of their ability to socialise and meet new people, although one of the females did say she modified her behaviour to suit the social situation she was in:

Sarah: “not at all when I meet people they have no idea that I have diabetes and I don’t let it get in the way of me making friends.”

Simon: “Um not really because like I’ve got um, got mates and stuff.”

Amanda: “like friends and stuff it’s ok because it’s just like something about me.”

Katie: “Um, not in general, but if I was at a function where I didn’t know many people it would. I’d be quite withdrawn I think, yeah, and I probably wouldn’t eat much or drink much or things like that.”

In regards to taking their medication in public places, all the participants except one of the males preferred to do it privately.

Jenny: “Well like at restaurants and stuff like if we go out for dinner I have to do insulin before I eat dinner and breakfast so I’d have to, cause if I like take my insulin here then go out I could get low so I have to do it there but I go into like a rest room or something to do it cause I don’t really want to do it like in the cubicle.”

Walter: “Some people are quite uncomfortable with it, so I sort of try to do it subtly, go somewhere else or do it quickly.”

Simon: “yep, yep. I do it in front of um my girlfriend and her ah friend, but all my mates at school and stuff it’s like they’re fascinated by it.”

Two of the participants talked about the flow-on effect T1DM can have on a family. Walter described his family struggling to adapt, for example they went through a process of altering how they ate as a family to accommodate T1DM:

Walter: “um it would of presented a lot of issues to my family when I was much younger.”

Jenny’s family has experienced a lot of long-term illness, her father has osteoporosis, her brother has epilepsy, cerebral palsy, and asthma, and her grandfather has T2DM.

She describes her two younger sisters wanting to get involved, and play an active part in helping the family members who have health issues with their medication routines and caring for them when they are not well so they feel useful and included:

Jenny: “at night when I do my insulin my little sister will go get my insulin out the fridge and carry it to me and she’ll wanna help me, she pretends she’s my table like when I do my blood test um my prick test thing she’ll want me to put it on her leg so she’s part of it too.”

The *Diabetes* magazine article discussed how in the Renouf family the mother found her children being diagnosed with T1DM as a very frustrating experience. She knew when they were diagnosed their bodies were still producing insulin, but that this would eventually end and neither she nor the medical professionals could do anything about it.

The *Off the rails* article reads as if it has been written for the parents of young adults with T1DM by a person who has real life experience of the restrictions they will be living with, and of the rebellion against T1DM they could currently be going through or facing in their future. The *Diabetes and Alcohol* article reads more like it is written for young people with T1DM, and gives practical guidelines drawn from the author’s experience, describing how she would recommend dealing with the restrictions of T1DM in a different way than her. She gave examples of how to deal with restrictions around food and alcohol, like avoiding beer which pushes up blood sugar levels due to its high carbohydrate content, making sure there are plenty of diet fizzy drinks available when drinking to keep sugar intake down, taking the daily recommended dose of insulin, and always having a blood sugar meter and glucose tablets on hand. It is interesting these articles were written as if for different audiences, but they were by the same author and published in the same magazine.

The interview participants were not so frank when asked about their participation in the common activities of their peer group, such as drinking alcohol socially and eating takeaway food, however the respondents did not appear to be too restricted, and

most did not limit what they had solely because of their T1DM. Some chose to have what they felt like at the time and compensate for it with medication later:

Sarah: "I allow myself to eat/drink whatever I like I just add in more insulin. I don't eat these foods often but if I want to I will and even if I don't it doesn't make me feel left out."

Simon: "Oh I don't, I just eat and drink whatever and um, cause usually in the holidays I just go back to work and I've got all my stuff there."

Jenny: "s'alright yeah, cause if I got out and stuff I just always have to have that with, like my medication stuff with me and I just have a handbag."

Walter: "I eat junk food. Oh it's fine, nah I just balance it up with the insulin."

Amanda: "I am not a big drinker and do not drink to get drunk and people respect that so that makes me feel better and not pressured to drink and I can always use it as a excuse if I don't want to drink or eat something which is quite handy."

One of the male participants chose to go without alcohol mainly due to his sporting commitments rather than solely because of his T1DM, but he did not believe drinking would cause difficulties for him if he chose to do it:

Walter: "Um, well I don't drink and that's [T1DM] part of the reason but I think if I wanted to drink it wouldn't really be a problem."

Two of the female participants said that they were mindful that they needed to be cautious with food and alcohol in order to maintain good health:

Jenny: "my mum had a talk with me about this like when I was about 15 16 but she said if you are gonna drink and stuff you just have to make sure that you have had your medication and that you test before and after, and that you're having snacks between. Like she realises that that is what ya know my age does but, yeah, you just have to be a lot more onto it than other people who don't have diabetes cause they can just conk out."

Amanda: “Junk food doesn’t make thing too difficult because I know I’m not allowed it I am not tempted. I can have junk food but just not as much as a normal person my age. It does get a little difficult when hanging out with friends when I need regular meal times and they just snack when they get hungry and have meals at random times. And also when we go out and decide to get something to eat and I do not have my injections means I can’t or if I do my levels will go up.

In the article about the Renouf family they are described as not blaming T1DM for the restrictions it places on their lives, but rather that they have learnt to accept that there are choices they need to make to stay healthy, as some of the interview participants had, such as:

“... deciding for example whether to eat cake at certain times because this also involves an injection.”

Two of the female participants said they had been eating more healthily since their diagnosis:

Jenny: “I used to before I got diabetes when I was 14 I was like ate so much junk food and was real unhealthy and, but since then I’ve changed like how I eat and stuff so it’s better for me really.”

Amanda: “But it has made me healthier and I may not be so conscious of what I eat if I did not have diabetes.”

A difficult question to answer was if they thought their lives would have been very different if they had not had T1DM. For the participant who had lived with T1DM the longest it really was not that easy to imagine. For the females the answer was more likely to be that it would be quite different:

Walter: “I think it would be very different, but not sure how.”

Sarah: “yes as if I didn’t have diabetes I would not be here in this moment of time. Getting diabetes changed my path in life so if I didn’t I would be on a whole different path.”

Amanda: “Um, I’d have like different groups of people and I’d look at things differently and different habits of day-to-day activities and stuff.”

The participants indicated T1DM does impose restrictions on a person’s life, there is a need to be organised in terms of a medication regime, and a need to compensate for anything consumed which is not part of a recommended diet. The author of the two *DYA Press* articles was obviously at a point where she was able to be honest about her period of flouting the rules in terms of alcohol and ‘bad food’, whereas the participants may not have felt they could be as open as her due to not having reached the same level of comfort with their condition. Although the participants would prefer to be T1DM free, in what they did feel they could talk about they did not report great stress as a result of the restrictions T1DM places on them, especially once they had worked out their own way to incorporate it into their social lives and identity.

Social Networking Site Use

The main SNS the participants used was Facebook. SNSs appear to go through phases of popularity with the participants; most started with Bebo but had moved onto Facebook. Only one of the female participants had started using Twitter which is a newer SNS than Facebook.

The time spent on SNSs was less than expected. It varied from an hour a week to three hours a day, with the most common amount of time being about three to four hours a week. The participant who spent the most time on SNSs used it as a general day-to-day communication tool because she did not get cell phone coverage at her home. All participants used Facebook mainly for communicating with friends and family, a secondary use was for looking at photos of friends and family. Two of the participants said they played the online games provided by Facebook:

Katie: “Oh I play their bejewelled on Facebook, I’m addicted to that.”

Walter: "Um mainly playing games."

On the whole the participant's 'friends' online were the same people they were friends with offline. They were open to being friends with people they had only met a couple of times offline, but would not accept a stranger as a friend online:

Amanda: "Um mainly people that I do know, there's a few like people that through other people that I've chatted to but not really, I try and stay clear of random people."

Walter: "I don't think I've met anyone through Facebook, but um a lot of people that I haven't had a lot of contact with from like other areas I've added as friends so."

Jenny: "Um a couple like, cause if you're friends with somebody it can like suggest that you add a friend of theirs and stuff as well, just like if you've seen people around like once or twice maybe your "Oh yeah I remember you" so you add them and you talk to them more. I don't really just add random people."

One participant found Facebook was a good way to get to know a person they had not had a lot of contact with offline, as it is a risk-free way to see if you want to spend further time with them, and if you do not you can 'un-friend' them and do not have to deal with them in person:

Amanda: "it is a good way to get to know new people better, after meeting someone new it is easy to add them on Facebook and get to know each other better without having to give them your number where they can contact you any time and you can also remove them or not accept them on Facebook."

The participant's current profiles were an accurate representation of who they were in an offline setting. Only one participant said they had previously had an online persona which was not totally accurate:

Walter: “No it’s quite different [Facebook profile], it’s more straightforward, just information and, Bebo was more entertainment.”

Also the participants did not see the point in trying different personas out online as the people they spoke to online knew them offline, and so it would be a futile exercise and recognised by friends as false:

Amanda: “No I’ve got friends that have done that, say that they own all these things and I just hate people who do things like that.”

Jenny: “nah [hasn’t tried experimenting with profile] not really I’m pretty straight forward.”

The response to a question about whether T1DM featured in the participant’s profiles was very similar across the board. They either had not thought about adding it to their profile, or they saw no need to display this information as primarily the ‘friends’ they had online already knew them offline, so if the participant wanted them to know about their condition they already knew. For four of the participants it was not so much that they had purposefully excluded the information, but none of them felt the need to let people who were not close friends know, also it really was not relevant to the socialising they did online:

Sarah: “No I just dont see the need in putting it there everyone who I am friends with on Facebook already know me so they already know that I have diabetes so I don’t see any point.”

Simon: “just haven’t thought about it to put on there.”

Amanda: “It just it hasn’t come up, it’s just not relevant.”

Two of the participants had actively chosen not to put their diagnosis online:

Jenny: “yeah it’s just, cause I have to like live with it every day and it’s just kinda pretty much always in your face it’s nice to have something to go to that you don’t have to worry about that.”

Katie: “doesn’t show cause I don’t like people to know.”

In saying this all participants said they would be happy to answer questions about their T1DM if asked in an online forum, as long as it was a genuine enquiry and not someone being insensitive:

Jenny: “oh it gets a bit annoying sometimes but, like if they don’t know anything about it I’m more than happy just to explain things to them, but other than that, like if it’s stupid questions then I don’t really bother.”

Katie: “cause if they were asking a question or wanted some perspective I probably would yeah.”

SNS use did not appear to interact with the participant’s creation of an identity inclusive of T1DM, and its use varied across the participants. SNSs could engender feelings of being in control of one’s identity and social context due to allowing the user to choose which aspects of the self got accentuated, and which aspects were left offline, and they could also help give young adults a sense of belonging to a group and with it add normality to their lives.

There was no specific SNS use discussed in the media articles, however both the *DYA Press* articles promoted the authors online blog site, which was described as an online community which could provide support to both young adults with T1DM and their parents. It is a site where people could learn more about their condition, and brainstorm with other people who have T1DM as to how to manage it successfully. This website also arranged offline meetings open to all the site users, to help build a network of peer support and a sense of community. This is a similar concept to the diabetes camps or conferences which the interview participants discussed attending, but perhaps has more of a social focus for young adults.

Summary

On the whole the interview participants and the media articles discussed T1DM pragmatically. Although it does present challenges and place restrictions on people’s lives, the participants and subjects of the media articles were not going to let it take

control or prevent them forming a confident gendered identity; however having a diagnosis of T1DM did lead to experiences and an identity which they felt may have been quite different had they not been diagnosed with it. As stated previously T1DM was part of who they were, but it did not define who they were. Further to this the interview participants were not going to allow others perceptions, if incorrect or ignorant, to have an impact on their lives; on the whole they were confident enough in their identity to not place too much focus on them. Support, be it from family, friends, the internet, books or medical professionals, although was not needed all the time was appreciated by all the people who were interviewed and discussed favourably in the media articles, and there was a sense that knowing the support was available allowed people to relax into who they wanted to be at that point in time.

The male participants in this study were very matter-of-fact in their approach to their T1DM. They acknowledged the differences it created in their lives, but did not perceive them as major hurdles to achieving what they wanted from life. The female participants were more aggrieved by the presence of T1DM in their lives despite their control of it; however most of them were able to see the positive side in that they lived healthier lives, and in keeping with an unconscious gender role were able to use their experience to support and care for others in need.

The category SNS use which emerged during the analysis of the participant interview data is not readily apparent within the media texts, and the perceptions of others and gender issues categories were absent. Further analysis of different media articles however could produce data which ties in with these three concepts. The media articles did tie in with the other themes which emerged from the interview data, as they talked about how feelings of support and control over T1DM and its restrictions can lead onto a person being able to include it into their identity successfully. There were no new categories found in the grounded theory analysis of the media texts which were not found in the participant interviews.

It is important to note that the positions the interview participants took in regards to their T1DM was quite possibly a reflection of the context they were in at that point in time. Firstly the participant interviews were carried out in three different types of

locations and one was solely via email, in addition if this research had used a different approach to gathering data the results could have been quite different; for example with a focus group approach participants may have engaged with a topic more in order to reinforce or disagree with points made by other people, or they may have felt more comfortable expressing a less socially acceptable position if they felt fellow participants held the same position.

The internet media texts could also be said to be one dimensional in viewpoint, specifically the subjects of the *Diabetes* magazine article and the TV3 news article, as what was presented to the reader would only have been a snapshot of the subjects' lives. As magazine articles and television news articles are not neutral information, but rather are written from a certain standpoint, I tried to take note of what was not discussed in the article as well as what was discussed. The two *DYA Press* articles were autobiographical and so could be thought to be fairly accurate. However the interviewers questions for the other two media texts, which the reader was not privy to, may have been formulated to achieve a certain tone for the article, and so it cannot be said with confidence that what was written was a thorough summary of the subjects experience of T1DM.

The tone of the *Diabetes* magazine article was particularly upbeat in terms of the Renouf family overcoming the challenges T1DM placed before them. Periods of poor control, or the physical side-effects of uncontrolled T1DM were not discussed at all. There may have never been any incidences like this in the family's lives, however they would be exceptional cases if this were true. Although it is understandable that this magazine would want to present a positive picture of life with T1DM for its readers, to admit everyone has failures at times, even sports stars, would give a sense of realism to the article which may be inspirational to someone reading it who is not in good control of their condition.

When the *Diabetes* magazine article is compared with the *DYA Press* articles it may reflect the differences in publications, the target audiences and the messages they are trying to convey. The *DYA Press* by its very title is aimed at a young adult readership, and so maybe tries to not come across as too heavily medically focused or this

population may not be inclined to read it. Medical professionals and parents might not see these articles as particularly helpful when viewing a person's lifelong health as a whole, in that although they do not advocate non-adherence to recommended T1DM control, they do provide realistic advice as to how to be a young adult still engaging in young adult practices whilst avoiding immediate health complications. Also the frank style in the youth magazine maybe encouraging of further reading on the author's blog site which does have more medically focused posts for the audience to read if they choose.

CHAPTER FIVE

DISCUSSION

Living with T1DM means having a life where health should be closely monitored and managed in order to ensure the absence of any of the complications associated with the condition. These demands on an individual require responsibility and control at a time of life when most young emerging adults would prefer freedom and spontaneity. Luyckx et al. (2008) found that if individuals with T1DM have a strong sense of who they are, they are able to develop sound strategies to integrate T1DM into their identity development, an integral part of the evolution from adolescence to adulthood and beyond. Although the participants in this research and the subjects of the media articles acknowledged they had a challenging life ahead of them, they had a determination to carry on with their lives as their peers did, and not let T1DM or others' perceptions control them. They considered T1DM to only be a part of the greater picture of their lives, and they felt this should be the case for anyone with a chronic condition regardless of gender or social context. For some of the participants having a chronic condition meant they had healthier lifestyles due to being more aware of their health and wellbeing, and also meant that as they were more attuned to the needs of others they were in a unique position to provide support.

I identified six concepts which emerged from the interview participants' talk about T1DM and identity formation. Control over T1DM was the key concept which underpinned most of their talk. The participants had not always had control over their condition which was similar to Balfe's (2007) findings. Going through this phase appears to be common in the acceptance of T1DM into a young adult's identity, but as the media articles discuss for most people it is not a permanent phase.

To help aid control over T1DM the interview participants and the media texts talked about being organised in regards to their condition. This included carrying blood sugar testing equipment with them and food high in sugar in case their levels went low. In contrast Balfe (2007) found most of their English respondents did not take their testing kit with them when they were out in social situations so as to avoid medicalising their identity. KyngÅs et al. (2000) and KyngÅs (2004) Finnish participants preferred to keep

their chronic condition a secret from peers, and risked their health in order to appear 'normal'; the media texts in this study encouraged young adults to educate family and peers in case of a medical emergency, also most of the participants reported they had someone with them who knew what to do in an emergency when they went out to socialise or to play sports. Although the three listed studies have differing results to the current participant population, it could be due to the studies being carried out in different countries, and also KyngÄs et al. (2000) and KyngÄs (2004) recruited participant groups with four different chronic conditions.

Once the participants had gained control over T1DM they indicated they were able to be confident in who they were and how they dealt with challenges in their daily lives. The other concepts (except one) were related to control, namely restrictions T1DM placed on their lives, gender issues T1DM posed, the support they received or gave to others, and others perceptions of their condition. Three of these concepts were also apparent within the media articles.

Different people in different stages of life draw on their own preferred sources of support. As stated previously support networks are associated with good health and good psychological outcomes, along with positive identity development (Cameron, et al., 2007). Peer support was important, as was a good rapport with health professionals for participants, however as Tilden et al. (2005) found there was a line which others could cross where their support changed into interference. Having a close relative who was also experiencing a chronic condition was helpful for participants. The lived experience of another was so much more inspirational than learnt knowledge, and the media texts illustrated it provided a feeling of shared understanding which would be missing in interactions with others. KyngÄs (2004) and Rasmussen et al. (2007) also found this to be the case in their research. Support can be found in many different guises and the media articles were very informative about different options. T1DM specific online communities were highlighted as being potentially able to fill a gap in a person's support network, however none of the participants chose to utilise these groups. It could be they did not feel they needed

this specific form of support, or they were simply not interested in belonging to a community which was focused around T1DM.

Although T1DM places restrictions on peoples' lives and those around them, it appears to be the individual person's attitude which determines whether they will allow the restrictions to take over. None of the participants were willing to let T1DM become the sole focus in their lives, even if they believed that eventually it would physically impair them. They strived to develop an individualised holistic health plan which worked in with the needs and priorities of themselves and their families. It is possible that one day the participants will find their approach to T1DM is not sustainable, however it is important for identity development that they can live their lives to the full and choose what is important to them at a particular point in time. The media texts encouraged parents to allow a young adult to take this approach as it results in happier and healthier lives in the longer term. Balfe's (2007) research findings and the media texts highlight if young adults are allowed to make their own choices in regards to their T1DM maintenance, given time a person with T1DM will adjust to their condition and become more conscientious about their health.

The participants had experienced social stigma, and as a result mostly preferred to take their medication in private when out in public to avoid people taking offence or casting judgement. Unfortunately this, along with eating or drinking what they felt like and making up for it with their insulin afterwards does reinforce Odegard and Capoccia (2007) and Balfe's (2007) findings that young adults with T1DM will try and hide their diagnosis and medical requirements depending on the social situation they are in. However although the participants have had some unpleasant experiences, more than anything they stated they had realised that most people were accepting of their condition, and they found the ability to not let ignorant remarks or T1DM take over their lives, thus becoming more secure in their management of T1DM and in their identity.

The participants in the study agreed there was confusion in the general populace around the different types of diabetes. There is a lot of media education being done around T2DM, and this perhaps needs more clarification so that people understand

there is more than one type of diabetes, but more especially that people who do get diabetes, no matter for what reason, are not socially irresponsible or solely to blame for their debilitating condition; the causes of T2DM are a combination of genetic and lifestyle factors rather than only because someone is overweight.

Dickinson and O'Reilly (2004) and Wilson (2002) found that their participants listed T1DM as the most embarrassing and disliked aspect about themselves. Although the participants in this study, and the subjects of the media articles, did not celebrate the fact that they had a chronic condition they certainly were not ashamed of it. They did not advertise their T1DM not because they were embarrassed, but because they wanted their lives to be about more than just their condition. Wilson's (2002) participant group included people from the age of 13, which may explain the differing results; both her study and Dickinson and O'Reilly's (2004) study were conducted in other countries. In this study it appeared it was others who had the difficulty seeing past T1DM rather than the participants themselves.

Previous literature does not draw definite conclusions as to how T1DM impacts a person's gendered identity construction. The male participants in this study did not see T1DM as having an impact on either gender, apart from during pregnancy, and felt it was not a big deal and people just needed to get on with life regardless of their condition. They asserted that they were healthy and would not lose control over their condition, and this was illustrated by them when they talked about how physically fit they were, and listed the different sports they engaged in. This finding is similar to that of Courtenay (2000), that in line with masculine stereotypes men perceive themselves to be invulnerable to ill health; however a difference with the males in this study from previous literature was that they claimed that they were happy to seek help from medical providers, but only if they really needed it. It is possible this response could have been made during the interview in order to appear socially responsible.

The female participants were a little more concerned in their responses. They felt at times it could be difficult to maintain their control over T1DM, and that it could interfere with physical appearance. These concerns comply with expected gendered

norms that females will be more aware and attentive to their health, and also with previous research (Wilson, 2002) which found that physical appearance and diet are important for females with T1DM in their identity development. The female participants who attributed some of the maintenance of control over their condition to being aware of the effects of T1DM on others also falls in line with the gendered norm of females being more inclined to worry about health and be nurturing of others more naturally than males. Despite the negative effects T1DM can have on a female's life, this study found it can also encourage females to live healthier lives as a result, which in turn is found to be beneficial for their physical appearance. This finding is encouraging as Williams (2000) found that once females found a reason to accept T1DM as part of their lives it enabled them to incorporate it into their identity successfully.

SNS use stood out as a separate concept from the others. Participants identified that although they did not use them, diabetic specific SNSs could be beneficial for people with diabetes, especially newly diagnosed people and their families. They can provide the capacity for people to socialise online and provide support where needed. In terms of using SNS pages to recruit participants for research projects, it is possible that people who would be willing to take part in a research study may not be those who would sign up to diabetic focused SNS pages. This is illustrated in the fact that in initial attempts to recruit through a diabetic SNS page yielded no respondents. Despite the growing use of the internet and the different modes in which people can communicate online, there is no guarantee that online interactions are authentic; the traditional and more personal approach of a mail out may be seen as more credible, and be more successful in enticing people to respond where they would not have online.

Although media allows for mass audiences it does not change the fact that individual attention is a limited resource, and despite a person potentially spending a lot of time on a SNS initially, this can wane as it merges in with other daily routines and social commitments. It could also be the case that with the number of different websites on offer people could sign up half-heartedly with no real intent to commit time to them long-term. Additionally, as is displayed in this research project, websites go in and out

of fashion and the participants really only had time to dedicate to the main SNS being used by their friends and family, in this case Facebook, the older SNSs such as Bebo became a less important use of their time.

SNSs offer a great deal of different activities to users, for example perusing 'friends' photos; having conversations with people, both in real-time and with email messages; joining webpage clubs and causes; and playing online games. The participants in this study only gave time to the SNS for the things that they really saw as important, communicating with friends and family. The majority of participants said that they were only friends with people online who they already knew offline, for this reason there was no point in any of the participants portraying themselves as any different online from how they were offline. It seems that rather than use SNSs as a way to recreate themselves, the participants used them more as a space where they could be themselves and not have to factor T1DM into their exchanges.

Implications for Young Emerging Adults with Type One Diabetes Mellitus

Medically recommended T1DM management has been found to be an issue for many young adults, but if they are able to incorporate it into their identity and not let it overtake them they may be more inclined to follow recommended medical protocols. For those participants and others who read the findings of this research, it may bring to their attention their identity construction in relation to T1DM and help them realise that they are not alone in their experiences, be they good or bad. To recognize there is a community of people who may be going through similar issues could be helpful, and influence them to seek out others for support or to give support where needed. It may also make this population more aware of the possible uses of SNSs and the support available over the internet.

Implications for Health Providers

Learning the most productive long-term way to help young adults with T1DM is a challenge for health professionals. As has been stated previously, the participant and media article analysis found best approach to treatment appears to be a holistic approach which is health focused rather than disease focused. The participants

involved in this research also stated they respect the opinions and support of medical providers who have lived experience of T1DM more than those who do not; it is possible that experience of any chronic illness would elicit that respect. The feasibility of attracting staff who meet this criterion in a role within diabetes clinics may be difficult, however it is definitely worth considering when looking at possible staff placements.

If the above is not possible, another approach may be to set up a local support group. This could have an online and an offline component, so that people with T1DM in the same area could make connections if they wanted to. The online site could perhaps be for all ages, and social get-togethers could be arranged for specific age groups. It would be appropriate for the support groups to not just focus on T1DM, but to encourage discussion about all aspects of daily life, in this way the condition is portrayed as an integrated part of a person's life rather than as the dominant part.

At the time of writing this thesis there was no information on the New Zealand Diabetes Society's website, or on the Waitamata District Health Board's website about the Dafne course which was discussed and highly recommended on the TV3 Campbell Live program. Many young adults rely on the internet for information, and the two sites above would be among the first sites people would go to for information after hearing the Campbell Live story. In a quick internet search for information about the program the only websites that came up were overseas ones with no local information. This needs to be amended and updated.

Future Research

To enable further knowledge to be acquired in regards to how the different genders cope with a diagnosis of T1DM, or any chronic illness, it could be beneficial for more research to be carried out which is targeted at the male population, as there are many studies which either focus on both genders, or specifically on females. The reason for this is so treatment approaches could be adapted to suit the individual and hopefully achieve better results.

The flow-on effect of T1DM on a person's family was discussed briefly with the participants. Previous literature suggests that T1DM has a negative effect, and can place a lot of strain on a family (Cameron, et al., 2007; KyngÅs, 2004; Rasmussen, et al., 2008), so to understand whether this is the case another research project would need to be conducted to further explore this.

As the internet is now so prevalent in New Zealand homes, further study which explores the best approach to recruit research participants via online webpages may be beneficial, especially for populations who potentially have identity or self-esteem issues. In addition, research into what would be considered attractive and useful by potential users of health specific SNS pages would be valuable information for those wishing to provide online support.

Limitations

This study involved a small number of respondents. With more interview data I could have been more confident that the categories which emerged from the line-by-line coding were the true opinions of the target group rather than of my own pre-conceptions on the subject matter.

It is probable that of the potential participant population, those who were not coping with the diagnosis of T1DM or who could not integrate it successfully into their identity chose not to respond to the advertisement for this research. Interestingly Balfe (2007) only had 11% of the potential pool of participants respond to their advertisement for research participants, and in Williams' (2000) study the male participants who refused to be interviewed were described by their mothers as not coping with their T1DM diagnosis. This could be one possible reason for the low response rate in the present study

Another limitation of the study was my inexperience as an interviewer and researcher. When I listened to the recorded interviews I realised that I interrupted respondents and put words in their mouth, rather than letting them come to their answer in their own time. On reflection I may have collected more in-depth data if I had not rushed through the interview schedule, I also could have explored points that were made by

respondents further if I had taken the time to consider their answers as they were given.

This study was designed to be explorative and descriptive to enable a framework to be developed about how young emerging adults' identity formation is affected by T1DM, and how this is portrayed online. The research explored and described the perspectives of a specific group from the diabetic population of New Zealand, which was purposefully selected using specific criteria, and cannot therefore be generalised to wider populations. Similarly choosing to study the young emerging adulthood portion of the population means these participants are possibly still 'emerging' and their views on their experiences and identity are likely to change again. This means the results of the study are only a snapshot in time for the people who took part and also for the media articles analysed. However the results could be a useful base for further study in the future.

Conclusion

Despite the limitations listed above this study has been found to support previous findings, which are that individuals who have a strong sense of who they want to be and how they would like to live their lives are able to avoid identity crises, integrate T1DM into their identity, and maintain that integration as they transition through their lives. It adds another opinion to the debate about how T1DM impacts on a person's gendered self, this being that it does not impact significantly.

This study adds to current knowledge by finding that SNS sites have the potential to provide holistic population specific support if utilised well. Although SNS use did not aid participants to incorporate T1DM into their gendered identity, they were regularly used and were an integral part of their general support network, which would assist them in their gendered identity construction.

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APPENDIX A: INTERVIEW SCHEDULE

INTRODUCTION

Are you living with your parents or do you have your own place?

What is your occupation?

SOCIAL NETWORKING SITE USE

Do you still use the same SNS's you listed in the Personal Information Sheet?

How much time on average would you use Social Networking Sites in a week?

What is the main thing you use Social Networking Sites for? Chat, photos, games?

When you are online do you mainly talk to people you already know offline, or do you also talk with people you have only met online?

Is diabetes part of your online profiles?

Do you purposefully exclude it from your profile and discussions with others?

If you use more than one Social Networking Site, are all your profiles the same?

Would the profile you have on your Social Networking Sites be the same person that you are in face-to-face encounters?

Do you ever try out different personas on Social Networking Sites?

Have you found support networks in regards to your diabetes on Social Networking Sites that you do not have offline?

Do you think these would be useful, or are useful to you?

DIABETES

How do you think living with diabetes influences who you are as a person?

Does Type 1 Diabetes restrict how you socialise with others?

How is it being in an age group where eating junk food and drinking alcohol is part of socialising?

Does it make it hard to make new friends? Or would it be easier to do this over the internet?

Do you try to hide your diabetes from certain people, or in certain social situations?

Do you know many others with Type 1 Diabetes?

If some of them are older people how does it feel for you to see the effects on people later in life?

Do people refer to you as a diabetic, and if so how do you feel about it?

Do you think your life be any different if you didn't have diabetes? If so how?

How do you feel about having to inject insulin?

Do you feel in charge of your treatment regime? Can the feeling change?

Do you feel in charge of your diabetes? Can the feeling change?

Do you think diabetes has more of an impact on men or women?

Are there aspects of being a man/woman which are affected either positively or negatively by your diabetes?

Does anyone help monitor your compliance with your treatment regimen?

How does it make you feel to have someone helping/not helping you with your treatment?

What is your opinion of your health carer's knowledge about Type 1 Diabetes?

Are there things in your life that you would prioritise as more important than your treatment regimen?

Do people confuse type 1 diabetes with type 2 diabetes?

How do you feel about confusion around diabetes?

APPENDIX B: INFORMATION SHEET



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ONLINE IDENTITY, YOUNG ADULTS, AND TYPE 1 DIABETES

Information Sheet

Hello, my name is Anna Eady and I am a Masters student in the School of Psychology at Massey University. I would like to invite you to take part in a study I am carrying out as part of my Masters Degree in Health Psychology. For this, I'm exploring how a group of young adults with type 1 diabetes create identities, both offline and online, using social networking sites.

Project Description

The aim of the study is to find out more about how living with type 1 diabetes influences a male or female adults' (aged 16 – 25) sense of who they are, and what part the use of social networking sites (for example, Bebo, Facebook, Twitter etc...) play in this. In this study I would like to interview approximately 10 young adults. Finding out about people's experiences will give health psychologists a better understanding of young adults with type 1 diabetes, and also how useful (or not) social network sites are for people with a chronic condition.

Project Procedures

If you choose to take part in this research you will be asked to participate in a confidential face-to-face interview with me, which will involve questions about how you include diabetes into your daily life, and how and why you use social networking sites.

The interview will be held in your home, or another suitable location of your choosing, and will take approximately 45 to 90 minutes. It will be audio-recorded and then typed out by me. As a thank you for your time and participation, there will be compensation in the form of movie vouchers.

Who Can Take Part?

You can take part in this study if you:

- ❖ Are living with type 1 diabetes
- ❖ Are 16 – 25 years of age
- ❖ Are a user of Social Networking Sites
- ❖ Live in New Zealand

Data Management

The interviews will be audio-recorded, downloaded onto a computer and typed out by me so they can be studied. All the information will be kept confidential and known only to myself and my supervisor. All the printed material, including reports, will use pseudonyms (made-up names) so you can't be identified. The transcript of your interview will be returned to you after the completion of the study, or destroyed after a five year holding period if you do not want them.

Participant's Rights

You do not have to accept this invitation; if you don't want to take part, that's fine and it won't affect any of your future health care if you do not join the study. If you are interested I will email you a Personal Information Sheet. If you answer the Personal Information Sheet's questions and send them back to me I will know you are interested in taking part in the study, and I'll get in touch with you to arrange an interview. If you decide you would like to take part, you have the right to:

- ❖ Use whānau support or a friend to help ask questions and understand the study;
- ❖ Decline to answer any of the questions in the interviews;
- ❖ Withdraw from the study at any time, without having to give a reason;
- ❖ Ask any questions about the study at any time during participation;
- ❖ Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- ❖ Ask for the recorder to be turned off at any time during the interview;
- ❖ Be given a copy of a summary of the project findings when it is finished.

If you take part in this study and you find you are uncomfortable with any of the issues it raises for you about diabetes or social network site use, please let me know and if I cannot help you I will give you a list of people you could contact for help with either diabetes or social networking site use in your area.

Project Contacts

Student Researcher

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Research Supervisor

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If you would like to take part or have any questions about this study you can contact me or my supervisor at the above email addresses. Thank you for taking the time to read this information and consider my request for your help in this study, it is much appreciated.

Anna Eady

*'This study has received ethical approval from the Central Regional Ethics Committee, ethics reference number **CEN/10/03/09**'.*

APPENDIX C: INFORMED CONSENT



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ONLINE IDENTITY, YOUNG ADULTS, AND TYPE 1 DIABETES

Participant Consent Form

- ❖ I have read and I understand the Information Sheet dated 04/02/2010 for volunteers taking part in the study designed to further understand how young adults with type 1 diabetes create identities, both offline and online via the use of social networking sites. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- ❖ I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- ❖ I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future health care/continuing health care.
- ❖ I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- ❖ I have had time to consider whether to take part in the study.
- ❖ I know who to contact if I have any side effects from the study, or any questions about the study in general.

I consent to the interview being sound recorded	Yes	No
I wish to have my recordings returned to me	Yes	No
I wish to have a copy of the results	Yes	No

A significant delay may occur between data collection and the publication of results.

I _____ (full name) hereby consent to take part in this study.

Date: _____

Signature: _____

Project explained by: _____

Project Role: _____

Signature: _____

Date: _____

PROJECT CONTACTS**STUDENT RESEARCHER****Anna Eady**

Phone : 06 8441424

RESEARCH SUPERVISOR**Dr Antonia Lyons**

Phone: 04 8015799 ext 62164

APPENDIX D: TRANSCRIPT NOTATION GUIDE

Transcription Notation

[C2: quite a [while Mo: [yea	Left brackets indicate the point at which a current speaker's talk is overlapped by another's talk.
=	W: that I'm aware of = C: = Yes. Would you confirm that?	Equal signs, one at the end of a line and one at the beginning, indicate no gap between the two lines.
(4)	Yes (2) yeah	Numbers in parentheses indicate elapsed time in silence in seconds.
_____	What's <u>up</u> ?	Underscoring indicates some form of stress, via pitch and/or amplitude.
WORD	I've got ENOUGH TO WORRY ABOUT	Capitals, except at the beginnings of lines, indicate especially loud sounds relative to the surrounding talk.
{laughter}	{laughter}	Any other significant behaviour – laughter, sighing, intake of breath, etc.
()	Future risks and () and life ()	Empty parentheses indicate the transcribers inability to hear what was said.
(word)	Would you see (there) anything positive	Parenthesized words are possible hearings.

APPENDIX E: ADVERTISEMENT

Private Box 756
Wellington 6140
New Zealand
T 64 4 801 5799
F 64 4 801 2692
www.massey.ac.nz

PARTICIPANTS REQUIRED FOR A MASTERS RESEARCH PROJECT**ONLINE IDENTITY, YOUNG ADULTS, AND TYPE 1 DIABETES**

Hi my name is Anna Eady. I am seeking participants for my Masters Research project on identity formation, online and offline, in young adults living with type 1 diabetes. If you have a diagnosis of type 1 diabetes, use social networking sites, and are between the ages of 16 and 25, I would love for you to take part in this research. It will involve a face-to-face interview (for about 90 minutes) with me in a location of your choice.

An information sheet is attached for you to have a look at.

If you would like to take part in this research, please contact me for further details at nad@netmail.co.nz and put 'research participant' in the subject line so I know it is not spam.

Thanks for your time.

APPENDIX F: EMAILED DEMOGRAPHIC QUESTIONNAIRE



Massey University
 COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
 Te Kura Pūkenga Tangata

Private Box 756
 Wellington 6140
 New Zealand
 T 64 4 801 5799
 F 64 4 801 2692
www.massey.ac.nz

PERSONAL INFORMATION SHEET

Please complete this screening questionnaire if you would like to take part in Anna Eady's research project:

Online Identity, Young Adults, and Type 1 Diabetes

Please read the Information Sheet attached to the email before filling in this questionnaire, so you know what the research project involves for you.

Once you have completed the questionnaire please return it to Anna at: nad@netmail.co.nz and she will contact you to set up an interview time and place, or you can opt to do the interview via email.

You have the right to decline to answer any of the questions, or withdraw from the study at any time.

Name: _____

Email Address: _____

Gender: _____

Age: _____

Which ethnic group do you belong to?:

- New Zealand European
- Maori
- Samoan
- Cook Island Maori
- Tongan
- Niuean
- Chinese
- Indian
- Other, please state _____

When were you diagnosed with type 1 diabetes?:

Which of the following social networking sites do you use?:

- Facebook
- Bebo
- Twitter
- Myspace
- Friendster
- Other, please state _____

APPENDIX G: TRANSCRIPT RELEASE AUTHORITY**Massey University**

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

Te Kura Pūkenga Tangata

Private Box 756
Wellington 6140
New Zealand
T 64 4 801 5799
F 64 4 801 2692
www.massey.ac.nz

ONLINE IDENTITY, YOUNG ADULTS, AND TYPE 1 DIABETES

Authority For The Release Of Transcripts

I confirm that I have had the opportunity to read and amend the transcript of the interview conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: _____ Date: _____

Full Name (printed): _____

APPENDIX H: ETHICS COMMITTEE APPROVALS

Corporate Services

HAWKE'S BAY
District Health Board

16 February 2010

Anna Eady
86 O'Dowd Road
Taradale
Napier 4112

Dear Anna

Re: Hawke's Bay District Health Board Research Application

Thank you for your application to conduct research within the Hawke's Bay District Health Board. I am pleased to advise that your application has been successful pending approval from the Central Regional Ethics Committee.

Please find enclosed a signed copy of your application and your Locality Assessment. I would appreciate a copy of the letter you receive from the Central Regional Ethics Committee.

Should you have any queries during your research, I can be contacted during office hours. It would assist if you quoted your registration number in any communication with this office.

Regards

Yours sincerely

**Alasdair Williamson RN MSc PhD Candidate
NURSE RESEARCHER**

RESEARCH OFFICE

Hawke's Bay District Health Board

Phone 06 878 8109. Fax 06 878 1686. Email: alasdair.williamson@hbdhb.govt.nz
Omahu Road, Private Bag 9014, Hastings, New Zealand.



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington

Phone: (04) 496 2405

Fax: (04) 496 2191

Email: central_ethicscommittee@moh.govt.nz

30 April 2010

Dr Antonia Lyons
School of Psychology
Massey University of Wellington
PO Box 756
Wellington 6140

Dear Dr Antonia Lyons

Ethics ref: **CEN/10/03/09**
Study title: Identity formation online and offline in type 1 diabetic emerging adults

The above study has been given ethical approval by the Central Regional Ethics Committee.

Approved Documents

- Information Sheet, Version 1, date 04/02/2010
- Personal Information Sheet, Version 1, date 04/02/2010
- Interview Schedule, Version 1, date 04/02/2010
- Advertisement, Version 1, date 04/02/2010

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report

The study is approved until **4 January 2011**. A final report is required at the end of the study. The report form is available on <http://www.ethicscommittees.health.govt.nz> and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried

out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study.

Yours sincerely


Sonia Scott
Administrator
Central Regional Ethics Committee
Email: sonia_scott@moh.govt.nz

APPENDIX I: ONLINE MEDIA ARTICLES

Youth Times

Family support for league star 'living with diabetes'

Video shots show Brisbane Broncos player Steve Renouf bursting tackles to score yet another try, with a jingle "Hi, now you're an all-star..." Delegates at the IDF Western Pacific Region Congress in Wellington were enthralled to see this athlete move to pulsating music.

Steve and his wife Elissa Renouf, parents of five children—four boys and a girl aged between 15 and 6—were at the Congress to share their story. Steve, now 37, having retired as a professional league player some five years ago, has Type 1 diabetes, as do three of their children.



Steven Renouf is considered one of the best centres in the history of rugby league. He holds numerous records for the Brisbane Broncos club and arguably is one of the greatest footballers to have played for it.

After spending 12 years with Brisbane, he played for the Wigan Warriors in the English Super League for two seasons before retiring from the top level of rugby league competition. In 2000 Steve was awarded the Australian Sports Medal for his contribution to Australia's international standing in rugby league.

Steve has a trade as an electrician and has also worked in sales and marketing. He currently works for the Queensland State Government as Indigenous Sport Ambassador.

In February 2006, a biography *The Pearl: Steve Renouf's Story* was released, detailing his career as a rugby league player. It also covers his early life, including his family heritage and his childhood in the Queensland town of Murgon, but also portrays how he, as an Aboriginal, had to overcome prejudice from people around him.

Steve tells how he was able to sustain his long playing career with diabetes. He signed with the Broncos at 17, making his debut in the first grade side in 1989, playing 46 seasons before being diagnosed in 1993 with Type 1 diabetes at age 22, not long after their first child Sam was born.

In 1992 Steve was having one of the best playing years of his life representing the Broncos, Queensland and Australia.

"Before I was diagnosed in 1993 we (Queensland) had won the Winfield Cup and I had played for Australia at Wembley Stadium and in the World Cup Challenge. Within weeks we had won everything that could be won."

Returning home from England after the three-week World Cup tour and World Club Challenge game he started losing weight, was very thirsty and had an infection in a wound after an operation.

Getting back to training in the off-season he was initially happy to lose 8kg until he found he couldn't lift weights.

He feared his professional league playing days were over, but then learned from the club doctor that his diabetes could be controlled, with one important proviso: that he had the right attitude for managing the condition.



Steve feared his professional league playing days were over, but then learned from the club doctor that his diabetes could be controlled, with one important proviso: that he had the right attitude for managing the condition.



Steve took up the challenge. "It was a personal attitude thing. I could let it beat me... or get on top of it and keep playing. I took up the latter... it's something (diabetes) you can live with."

He went on to play in four winning grand league finals, nine tests for Australia, including one super league test, and 11 State of Origin games for Queensland. He retired from playing in the National Rugby League competition in 1999 after signing a two-year deal with English club Wigan Warriors.

He made his test debut for Australia on the 1993 tour of New Zealand when he replaced the suspended Australian captain Mal Meninga. Injury meant Steve played only one of the tests against New Zealand in 1993, but he bounced back to score three tries in the one-off test against the touring French side.

By keeping tight control of his blood glucose levels through diet and insulin injections he was able to achieve his goals, and survive many bone-crunching tackles along the way.

Steve believes his attitude, the ongoing support of Elissa, and the involvement of all members of his cohesive family unit have been critical factors in his being able to sustain such a long and successful playing career.

Important too was acceptance of his condition by his mates. "I thought, how do I handle it with the team?"

We were spending a lot of the time on the road, travelling everywhere together, so I decided to let them know.

"The guys were great. It's important for them to know there is someone with diabetes. And there comes a time too when you might need them (to help)."

Steve and Elissa went on to have another two children Billy and Sunita. Elissa recalls that when Sunita was 6 months old, she (Elissa) developed Graves Disease (over-active thyroid) which also is an auto-immune condition.

"I treat this with tablets which keep my levels under control. We often wondered whether the children had a risk of getting one of the diseases but were told that they had only about 5% chance."

Steve and Elissa had another two children Charlie and Freddie. All the children seemed healthy until May 2002.

Just after Charlie's third birthday one night when he was going to bed he asked his mother to fill a drink bottle with water. The first thing he asked for when he woke the next morning was for her to fill the drink bottle again.

"As we had tested the children on Steve's meter every now and then and they were all fine, I was not really alarmed but asked him if I could test him on Daddy's tester."



Youth Times



Steve with eldest son Sam.

"He didn't want to do this so I thought that I would just test him when he went to sleep that night. When we did test him his level was 21mmol/L. We phoned the hospital and they asked that he be taken in right away."

Charlie started on insulin injections the next morning. "We were very lucky that we had knowledge about diabetes and diagnosed it before he got very ill."

"Charlie accepted the insulin injections and everything that goes with having diabetes very well. We put this down to the fact that he had always seen Steve do everything so it wasn't as scary as it is for children who have never seen the needles before."

By early January 2003 Elissa and Steve felt they had everything under control with Charlie's diabetes but then noticed Billy, 8½ years old at the time, was showing symptoms of diabetes.

"We tested him all that day and by afternoon knew that he too had developed diabetes. He accepted this very well and already understood a lot about diabetes because of Charlie."

Billy was also diagnosed with coeliac disease in May 2003, which means he can't have any foods that contain gluten.

Over the next few months Elissa and Steve kept on testing the other children and by October 2003 noticed that Freddie, their youngest child, was showing early signs of diabetes.

Elissa found this a particularly hard time. "Freddie was

still producing insulin but this was slowly decreasing – why can't I stop this from happening?"

By March 2004 Freddie started on insulin injections just two months before his third birthday. "He also accepted this very well because he was going to be like Dad and his two other brothers." Freddie, like his brother Billy, went on to develop coeliac disease in November 2005.

Elissa says that throughout all challenges faced as a family they have tried to keep positive. "We don't blame anything on diabetes."

Their children with diabetes are learning to make choices, deciding for example whether to eat cake at certain times because this also involves an injection. "The 3-year-old will choose the cake and the needle," laughs Elissa.

At the Congress the Renoufs displayed a range of diabetic products which they developed to provide compact consumables for all people living with diabetes.

"As a lot of the diabetes companies are not living with diabetes on a day to day basis I feel that we have the knowledge and practical experience of what is needed to make our lives and yours just that little bit easier." ♦

If you are concerned that a family member may have diabetes or is experiencing symptoms of diabetes please seek advice from your family doctor.

Article: Lance McEldowney, Editor diabetes

Having a life with diabetes

This is a new page aimed at diabetics in their late teens and early twenties. Nic Reade is a 31 year old who was 16 when she was diagnosed with type 1. Her style is deliberately frank and light-hearted but also offers up some practical advice. For medical queries please ask your diabetes team.

I was 16 when I was diagnosed with type 1, so was still a bit of a newbie by the time I got to university age, the time in many young peoples' lives when alcohol becomes a bit more of a key player in your social life.

I'd read that alcohol could make your blood sugars plummet, so my usual routine on a Saturday night would be to sneak into the kitchen and wolf down a couple of chocolate biscuits. I was still living at home so I needed to be a bit covert about this or there would be questions asked about why the chocolate biscuit supplies were declining!

So – basically, that's how I used to handle T1 and drinking. Get the sugars nice and high, get drunk, eat food at the party/on the way home, but always take my night time injection. Somehow this vaguely worked for me all the way through my late teens and early twenties. I've got lots of friends who weren't so lucky though, most of whom have had to go to the A&E once or twice with ketoacidosis (never normally hypos). I say 'vaguely' worked, because my HbA1cs were always around 9 or 10.

So – if I were to live my uni days again, what would I do differently? First of all I'd chuck the biscuits and high BGs routine. Combined with drinking fattening alcohol, this led to me putting on quite a few kilos. I still reckon it's probably a good idea to have your BGs at around 10 though while drinking, to be on the safe side.

Secondly, I'd definitely make sure I took my BG meter out with me. They're much smaller and cooler-looking nowadays and you can fit them even in the smallest of handbags with a few test strips and the rest of your stuff. I'd also take glucose tablets. I always used to rely on being able to get a lemonade, but if you're at a bar it can be a bit of a wait to get a drink and that's not cool when you're hypo.

I'd also drink less beer. Because beer's full of carbs it's not only fattening, but it's hellish on your BGs. Wine is better; clear spirits even better still. It's easy to drink vodka and diet coke at a bar, but I still wish they had diet lemonade so you can have a bit more variety in drinks. I got into drinking vodka, lime and soda for a bit but got sick of checking if it was lime cordial (bad) or Roses lime (good). The annoying thing about parties (as opposed to bars) is if you leave your diet mixers in the kitchen with everyone else's, there's always someone who fancies using it for their drink. When the diet stuff runs out, you can't move onto sugary stuff – they can switch between the two. Annoying.

I used to avoid telling people I was T1 when I was out drinking because I didn't want them to judge me. However, I nearly always had my best mate by my side who was well-versed in what to do if I went low. It wouldn't have been a bad idea to tell a couple more people though, in retrospect, given that being hypo and being drunk can sometimes look like the same thing.

I recently read a book written by a 23 year old English guy who got T1 at 13. It's called "Joe's Rough Guide to Diabetes". At 23, he's had a bit of hands-on experience with parties, and does a whole chapter on alcohol (and a bit on cigarettes and illegal drugs). He approaches each situation well – not as a kill-joy, but with some degree of sensibility. I'd highly recommend.

Overall – it's gonna be hard to avoid alcohol, and all of us (diabetic or not) make a mess of it at least once in our lives. Just try to keep safe, and overall, make sure you keep taking your injections and always carry glucose with you. Party on!

For more stories from Nic visit her blog at www.beingdiabetic.co.nz



Having a life with diabetes



OFF THE RAILS

I went for my six-monthly Endocrinologist appointment the other day. I have a lovely doctor, who has been my specialist since I was diagnosed at 16. He's always been pretty realistic about what teenagers and twenty-somethings get up to, and has always had a good way of communicating with me as I've grown up.

He looked through my latest blood results. "Everything's looking good. You've had this condition for 16 years now – half your life – and not a single complication. That's a huge pat on the back for you in terms of managing your diabetes successfully all this time," he said.

At that point I had to clear my throat and challenge his statement. "Ummm. Well, you COULD say that," I said, "but there were a good few years there you'd be lucky to see me do a couple of blood tests a week." (and if I'm reeeeeeally truthful I would actually say a couple of blood tests a MONTH)

The truth hurts, but is also a little liberating. To be honest with you, I really did my best to ignore my diabetes from the ages of 19 through to about 26. I kept up with my injections, and managed to avoid any hospital admissions, but had HbA1cs in the high 9s and 10s the whole time. I also took full advantage of over-full outpatients departments in Auckland and London who didn't have time to tell you off if you cancelled appointments, and would then have to give you the next available one several months down the track. I think at one stage I managed to avoid going to the diabetes department for almost two full years.

So – the questions you parents of T1s may be asking are – "is every young person with diabetes like this? Will I have to put up with the normal teenage rebellion and moodiness as WELL as diabetes non-compliance?". Sorry to be a realist, but the answer is: almost definitely.

A quick poll of a group of my T1 friends in their 20s and 30s backs up my theory. Almost all of them had an "off the rails" period with their diabetes – most of them during university/early flatting years. They wanted not to stand out, they wanted a spontaneous life, they wanted rid of their chronic condition.

The good news is – these people are friends of mine now because they've joined my diabetes community on www.beingdiabetic.co.nz. These naughty teens are now actively reading news about type 1 and how they can manage it better. They are coming along to dinners with other T1s and seeking ways to fit diabetes in with their lives, in order to be healthy and happy.

They cite different reasons for their return to diabetes control. Some of them have done it in order to get their sugars ready for pregnancy (or to live a healthy life for their children). Others have just grown up and realised they're not ten feet tall and bulletproof. Others have done it to achieve well in sport. I think there is also an underlying respect (now that they're older) for the complications which could affect them in later years.

So – how best do you manage a teenager/twenty-year-old when they're doing their best to ignore their condition, and you're

worried sick? I read a fantastic book recently, called "Diabetes Through the Looking Glass. Seeing diabetes from your child's perspective" by Dr Rachel Besser, a paediatric specialist in the UK who has T1 herself. The book explores exactly what the title suggests, and there is a great chapter on 'the teenage years' which had me nodding sagely. Definitely worth a read if you can get your hands on it.

Overall, my message on this topic is – there are likely to be a few years where your child goes off the rails a little. But don't waste too much time worrying about it: they'll grow out of it, and learn to take charge when they're ready. It will be tricky for you to know how to deal with this, but don't be too hard on your child: after all, this is a condition they'll have to cope with every single day for their whole lives.

This page is aimed at diabetics in their late teens and early twenties (and their parents). Nic Read is a 31 year old who was 16 when she was diagnosed with type 1. Her style is deliberately frank and light-hearted but also offers up some practical advice. For medical queries please ask your diabetes team.

For more stories from Nic visit her blog at www.beingdiabetic.co.nz.



TV3 Campbell live transcript

Type one diabetes - an unavoidable curse

Friday 19 November 2010

More than 200,000 New Zealanders have diabetes, and many more are at risk of contracting it.

But while type two diabetes is avoidable, for the thousands of New Zealanders with type one diabetes, it's a different story.

Type one is passed on genetically, meaning sufferers have to monitor their blood sugar levels, and inject themselves with insulin several times a day, every day, for the rest of their lives.

Lachlan Forsyth spoke with three people living with type one diabetes.

-Max Rogers (diagnosed 3 weeks ago?)

-Alfrey Bloom

-Win Johnston (had it for 75 years, diagnosed at 7, now 82)

AB: Basically I would have died, I um quite simply generally what will happen is a person will kind of be going about their normal life, they will have the extreme weight loss have the thirst think 'oh it's all good you know weight loss is great we all want to do it', and they'll keel over and they'll go into um sort of a diabetic coma.

MR: Yeah it was about three weeks ago, yep and I was just a bit sick and so I went to the doctors and then they just took me to hospital.

WJ: Ah 75 to be exact, I was 7 when it was diagnosed, and I'll be 82 in two weeks time

AB: Basically wherever I go I have to take insulin and I have to take jellybeans, and I take my test kit, so at any stage during the day I might find that my blood sugars go low and when that happens it's, it's a really horrendous feeling, basically it kind of feels like you're falling and your hands start to shake and you feel really nervous and really jittery and you kind of get some symptoms almost like you're drunk.

WJ: You see you've probably heard about hypos well the sugar drops so low, well they didn't even tell us what that meant and the first hypo I ever had was when I, the day I graduated as a nurse and I collapsed in the ward, they carted me down to A & E in Wellington and said, 'well what have we got here?' and I said 'you tell me' [laughter]

MR: If I'm doing exercise usually my blood sugar will drop, so I should take carbohydrates to just get it back up but if it's quite intense sometimes it goes up, my blood sugar, cause you release like hormones or stress hormones which take it up

AB: sport for me is a real challenge, um there's a lot of calculating that goes into it, there's how much have I eaten that day, what insulin have I had that day, how vigorous is the sport going to be..

WJ: Swimming, I'd always have to do a test, just a urine test because there was nothing else to show it, not like the meters we've got now, and ah we just had to take it by the colour of the urine.

MR: I just have to be a bit more careful, and aware of how I'm feeling when I'm running, so I'll carry like some lollies or something to boost my blood sugars up if I go low.

AB: Now that I've been on the Daphne course I can carry on a lot more normally than I ever thought I could, to be honest before I went on that course I'd kinda decided I wouldn't make it much passed 30, my life just wasn't going to carry on cause I's so ill all the time.

WJ: I never knew when it was going to happen, and ah it sort of got lower and lower and lower, now I can recognise them coming hopefully I don't get too many now, but um I think you know that on the whole I've been very, very lucky.

AB: So it's not cancer or anything like that, but I'll have it for life, and it will affect my life forever, and it will likely get worse as I get older. Um I think if this is the only you know negative health thing that happens to me then that's ok, um but I tell you what if I get some other horrendous condition too I'll feel pretty hard done by.