

**The Role of Autonomy in the Self-Management of Exercise in Emerging Adults with
Type 1 Diabetes – An Exploratory Study**

**A thesis submitted in partial fulfilment of the requirement of the Degree of Master of
Science in Child and Family Psychology**

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Abstract

Successful self-management of Type 1 diabetes mellitus can prevent potentially life-threatening effects. Responsibility for diabetes management, including exercise, is increasingly transferred from parents to adolescents throughout adolescence and successful transitions are linked to better health outcomes.

The aim of the study was to explore the role of autonomy in participants' self-management of exercise behaviours and the transfer of responsibility throughout adolescence.

The design of this study used qualitative description with information collected and presented using a case study approach. Participants were five emerging adults (aged 18–24) with Type 1 diabetes for a minimum of one year who lived in Canterbury. Data was gathered through three sources: a semi-structured interview seeking self-reported exercise throughout adolescence, a set of questionnaires based on four instruments, and physical activity performed over a week as recorded by an activity monitor.

All participants achieved autonomy for exercise, however participants achieved autonomy at different ages. Participants' diabetes self-management and physical activity levels varied according to their stage of life and lifestyle. They received varying advice about exercise from health professionals. Participants sought to determine their own exercise choices during adolescence, leading them to obtain a driver licence to be independent of parental transport.

Three of the five met current guidelines for physical activity levels, and another met recommendations by her clinician. Policy implications regarding healthcare advice and barriers to exercise for young people are discussed, as are limitations of the research and future avenues for research.

Chapter 1

Introduction

Type 1 diabetes mellitus (T1D) is a chronic condition that usually begins in childhood and requires careful management for the rest of the patient's life. Although it is less common than the related condition Type 2 diabetes mellitus (T2D), T1D is a condition which is worthy of consideration for several reasons (Daneman, 2006). It is usually diagnosed in childhood and is a lifelong condition, which means in terms of the burden of disease, there is a greater impact case-for-case than some other conditions. Additionally, the risk of developing secondary complications of T1D increases with the length of time since diagnosis of T1D and diagnosis of T1D is typically made early in the lifespan. Unlike T2D, prevention is not an option for T1D. Finally, the incidence of T1D is rising globally, nationally and locally in the Canterbury region.

Definition

Diabetes mellitus is a group of related metabolic disorders that lead to high blood glucose levels and problems with metabolism (Alberti & Zimmet, 1998). T1D is a disorder that occurs when cells in the pancreas called islet beta cells are destroyed and no longer produce insulin, the hormone that regulates glucose levels in the blood. Insulin is necessary so that the body can use glucose from the blood for energy. T1D is primarily an autoimmune disorder but may also occur idiopathically in rare cases (Alberti & Zimmet, 1998). Although it is not known exactly why some people develop T1D, it is thought that an infection triggers an atypical immune reaction in the body in a child who is more at risk of developing one (American Diabetes Association (A.D.A.), 2012a). Some of the early environmental risk factors are thought to include infections within the womb, increased maternal age, conditions such as pre-eclampsia during pregnancy, increased birth weight and accelerated growth after birth, and lack of early exposure to Vitamin D (Solez, Patterson & Dahlquist, 2007). Recent

research from New Zealand suggests that the mechanism causing both T1D and T2D relates to a build-up of the hormone amylin in the pancreas, leading to cell death of the beta islet cells which produce insulin (Zhang et al., 2014). Other recent research has pointed to the role of Thioredoxin-interacting protein (TXNIP) in promoting amylin (Jing et al., 2014; Shalev, 2014).

In a typically functioning person, blood glucose levels rise after ingestion of carbohydrates, and the pancreas responds by producing enough insulin to allow cells to store and use the glucose. However in a person with T1D, insulin is not produced, glucose is not regulated, and blood glucose levels may increase leading to hyperglycaemia (or high levels of blood glucose) or decrease leading to hypoglycaemia (or low levels of blood glucose). Keeping blood glucose levels within a narrow, healthy range is also known as glycaemic control or metabolic control. T1D was formerly known as insulin-dependent diabetes mellitus, or juvenile-onset diabetes mellitus. It is diagnosed most frequently in children and adolescents, but may occur at any age during the lifespan and is increasingly being diagnosed in adults (A.D.A., 2012a).

Complications

Both the short- and long-term complications of the disease are extremely serious, and are associated with costs to both the individual and to society. Because the brain uses glucose for energy, brain functioning is affected by low blood glucose levels. In the short term, hypoglycaemia can cause feelings of intense hunger and dizziness. Severe hypoglycaemia can lead to convulsions and unconsciousness. In the long term, repeated and severe hypoglycaemia can lead to permanent cognitive impairment (Delamater et al., 2001).

There are also serious short- and long-term effects of high blood glucose levels. In the short term, acute hyperglycaemia can lead to thirst, increased need to urinate, weight loss, inhibited growth and blurred vision (A.D.A., 2012a). If the body cannot access blood glucose

for energy using insulin, it starts to use stored fat for energy instead. However, the breakdown of the fat creates by-products called ketones, and if the blood concentration of ketones reaches toxic levels it causes a condition called ketoacidosis, which can lead to coma and death if untreated. In the long term, sustained high levels of blood glucose is toxic to organs. Long-term effects of hyperglycaemia include complications such as permanent damage to nerves (neuropathy), eyes (retinopathy), kidney (nephropathy), heart and the cardiovascular system (microvascular and macrovascular complications), foot ulcers, lower limb amputations and stroke (A.D.A., 2012a; Diabetes Control and Complications Trial (DCCT) Research Group, 1993; Funnell et al., 2009).

Management of Diabetes in Adulthood

Best practice management of T1D is intensive management of symptoms through developing an individualised treatment plan between the patient and their healthcare team (Funnell et al., 2009). The aim of the plan is to keep blood glucose levels within a healthy range thereby reducing the risk of future complications. An intensive diabetes management plan, or “tight” glycaemic control, includes frequent blood glucose checks and insulin injections to ensure that blood glucose levels do not rise too high or fall too low, and takes into account the effects of diet, exercise and illness, among other factors. A large longitudinal study, the Diabetes Control and Complications Trial Research Group (DCCT) (1993) followed 1441 people with diabetes over an average of 6.5 years, and found that people assigned to a group with more frequent checking and insulin administration developed fewer long-term complications such as retinopathy than those assigned to a control group with less frequent checking and administration. This study proved conclusively that the complications associated with diabetes were caused by elevated levels of blood glucose over a prolonged period, and that by reducing blood glucose levels the risk for complications could also be reduced.

Intensive diabetes management is therefore considered best practice, and is necessary to reduce the risk of serious negative health outcomes in the present and the future. However, intensive management is also associated with a higher proportion of hypoglycaemic episodes than non-intensive management (DCCT, 1993). Maintaining such a narrow range of blood glucose is difficult, and requires both constant vigilance and experience in adjusting the different aspects of diabetes management.

Aspects of diabetes management. Daily diabetes management generally falls into four main aspects: multiple daily blood glucose testing, insulin delivery, diet and exercise (Silverstein et al., 2005). Glucose levels are monitored in the short term through use of a blood glucose meter, where the person with T1D pricks his or her finger, places a drop of blood on a special strip, and obtains a reading almost instantly. The reading indicates the level of glucose in the blood, and the person then calculates the amount of insulin needed. Blood glucose levels can also be monitored over a longer period through regular blood testing by clinicians of glycosylated haemoglobin, which is also known as HbA1c or glycohaemoglobin. This is the average blood glucose level over the previous two to three months, and provides feedback so that a person with T1D can see how their average blood glucose levels have compared to levels where long-term complications can occur (A.D.A., 2012b).

Insulin is administered either through multiple daily injections or through a pump called a continuous subcutaneous insulin infusion (CSII) (Wiebe et al., 2010). Both methods require blood testing throughout the day, with additional insulin administered at mealtimes three or more times a day (A.D.A., 2012b). Patients can use long-acting insulin, rapid-acting insulin or a combination of both to keep insulin levels in the ideal range. There are many factors that can affect the amount of insulin needed, and these will be discussed further in the following chapter. At its most basic level, the amount of insulin to be administered is

calculated depending on the person's blood glucose level and the number of carbohydrates eaten or about to be eaten. This method is described as "carbohydrate counting" or "carb counting" by the A.D.A. (Bantle et al., 2008) as carbohydrates must be closely monitored to maintain relatively level blood glucose readings.

Diet plans should ideally be personalised depending on the patient's individual needs, according to the A.D.A. (Bantle et al., 2008). The plan should preferably be designed with consultation from a nutritionist and take into account: Aims for near-normal blood glucose and blood pressure levels; the person's current physical health and risk of future complications; nutritional needs for their stage in life; motivation to make changes, and including a wide range of foods unless otherwise contraindicated (Bantle et al., 2008). In general, diet should include healthy food, rich in nutrients including fresh vegetables, fruit, grains and fat-reduced milk (Bantle et al., 2008). Using data obtained from the DCCT, Delahanty and Halford (1993) found that patients who reported keeping to a meal plan, and who responded to hyperglycaemia by adjusting their diet and/or insulin doses, had lower long-term blood glucose levels than patients who did not.

Exercise is another key aspect of diabetes management, and is an area of diabetes research which has attracted relatively less research. In general, exercise and physical activity are associated with a number of benefits in health and wellbeing, such as improved cardiovascular fitness, improved muscle tone, improved mental health and a reduced risk of developing future illnesses such as heart disease, some forms of cancer, stroke and Type 2 diabetes (Physical Activity Guidelines Committee, 2008).

For people with T1D, regular exercise can have additional benefits such as a temporary increase in insulin sensitivity with a lower need for insulin, better cholesterol profiles and lower blood pressure (Maahs, Taplin & Fiallo-Shearer, 2009). Crucially, an article analysing data from the EURODIAB study, a longitudinal multi-country study, found

that physical activity was inversely associated with all causes of mortality in people with T1D and in particular was inversely associated with death from cardiovascular events in women with T1D (Tielemans et al., 2013). Despite the many benefits of exercise, the issue is complex because there are also risks involved for people with T1D due to their body's inability to regulate their insulin levels during physical activity. Therefore, exercise plans should ideally be individually developed in consultation with a sports physiology expert after the patient has received a thorough health check and has received a screening for complications (New Zealand Ministry of Health Guidelines, 2014). Exercise for people with T1D will be discussed in greater depth in the following chapter.

Permanent treatment of diabetes. Research in this area is experimental and has met with mixed results. Some research has focused on preventing further destruction of beta islet cells in the pancreas by the immune system at the time that T1D was first diagnosed, when some cells are still viable. Glandt, Hagopian and Herold (2003) found that by immobilising the antibodies attacking beta islet cells in the pancreas in newly-diagnosed people with T1D, they were able to prevent further destruction of cells, and found blood glucose improvements in some participants. Continued improvement was shown at two-year follow up (Herold et al., 2005) and at five-year follow up (Herold et al., 2009). In terms of a cure for those without remaining beta islet cells, for many years there was no cure.

One area of research has investigated the effects of beta islet cell transplantation. Although early studies found that the transplanted cells were attacked and destroyed by participants' immune systems in the same way that their own beta islet cells were attacked, later studies have added adjustments in immunosuppressant therapy, but long-term effects of these transplants are still unknown (Ryan et al., 2002). More recently, research has focussed on stem cell treatment (Hussain and Thiese, 2004). Early results appear promising, but positive results seem to be negatively associated with an episode of diabetic ketoacidosis, as

participants who had experienced ketoacidosis achieved much lower remission rates than those who had never experienced ketoacidosis (Gu et al., 2012).

Additionally, Voltarelli et al. (2007) achieved mixed results using immunosuppression and stem cell therapy with 15 participants who were newly diagnosed and who had never experienced an episode of diabetic ketoacidosis. However, as the diagnosis of T1D is often made through an initial presentation of ketoacidosis (A.D.A., 2012a), this finding indicates that stem cell therapy may not be effective for everyone with T1D. Recent research producing mass beta islet cells from stem cells has demonstrated the resumption of insulin secretion in diabetic mice, but human trials are yet to begin (Pagliuca et al., 2014). Likewise, one study has successfully used a statin called verapamil to inhibit TXNIP, thereby reducing amylin and restoring beta cell functioning in diabetic mice (Xu, Chen, Jing & Shalev, 2012). However, trials in humans are yet to begin. Although a cure may be possible in the future, at the present time there is no cure for T1D and self-management remains the only way to prevent serious health complications in later life.

Incidence

Worldwide incidence. This section includes both studies describing the incidence, or number of new cases of T1D during a period of time, and the prevalence, or number of existing cases of T1D at a point in time or during a period of time. There are several large-scale studies which have focused on the increasing incidence of T1D worldwide. The DIAMOND study conducted by WHO investigated the incidence of T1D in children aged up to and including 14 years in 50 countries from 1990 to 1994 (Karvonen et al., 2000; LaPorte, 1990). The authors found that there was a large variation in incidence per 100,000 population between countries, with over 350-fold difference between countries with the highest and lowest incidence (36.5/100,000 – 0.1/100,000 population per year). New Zealand was ranked sixth highest of the countries that took part in the study, with incidence rates in Auckland

found to be 12.9/100,000 population and incidence rates in Canterbury found to be 23.9/100,000 population (Karvonen et al., 2000). A study of worldwide incidence of T1D by Onkamo et al. (1999) reviewed 37 longitudinal studies conducted in 27 countries over a period of 36 years. The authors found that the overall incidence of T1D in children aged up to and including 14 years was increasing at a rate of 3% per year and that incidence increased with children's age. Similarly, Maahs et al. (2009) reviewed studies on the worldwide incidence of T1D and found that it is increasing by 2–5% worldwide. The EURODIAB study, a large scale study including data from seventeen European countries, found that for children aged 0–14 years, there was an overall annual increase of 3.9% between 1989 and 2003, and incidence was predicted to double between 2005 and 2020 (Green, 2001; Patterson et al., 2009; Stephenson & Fuller, 1994).

New Zealand incidence. New Zealand has comparatively high rates of T1D compared to the rest of the world and incidence is increasing over time. Campbell-Stokes & Taylor on behalf of the New Zealand Children's Diabetes Working Group (2005) investigated the incidence of diabetes mellitus diagnosed in New Zealand children and adolescents aged under 15 years in 1999 and 2000 using data gathered through paediatrician report. The authors found that 298 cases of T1D were diagnosed in children and adolescents aged 0–14 years with an average incidence of 17.9 per 100,000 population over the two-year period, and noted that this represented twice the incidence rate that existed 30 years earlier. Campbell-Stokes et al. (2005) also found that incidence was higher in the South Island than in the North Island and that incidence varied according to the ethnic backgrounds of children and adolescents, with the highest incidence among those of New Zealand European descent. This is consistent with international studies which have found that the risk of developing T1D is higher in populations of predominantly Caucasian ethnicity (Karvonen et al., 2000). Willis, Scott and Darlow (2005) wrote a reply to Campbell-Stokes et al. (2005) indicating that the

results of their two-year study should be interpreted with caution. Willis et al. (2005) noted when incident cases were aggregated over a longer period of time, there were peaks and troughs spanning two to three years and that using a two-year section of data may lead to inaccurate conclusions.

Another study by Wu et al. (2005) extrapolated data from the Canterbury region to estimate the prevalence of T1D in young people aged 0–24 years in New Zealand. Wu et al. (2005) found that the prevalence of T1D in Canterbury, New Zealand was 227 per 100,000 population and calculated that if extrapolated to the population of New Zealand, there would be an estimated 2540 young people with T1D throughout the country. However, Wu et al.'s (2005) calculations do not take into account the varying rates of T1D between regions in New Zealand.

Canterbury incidence. The incidence of T1D is high in the Canterbury region and is increasing. All new prospective incident cases have been aggregated and recorded in the region since 1982 by the Canterbury Register of Incidence Treated Persons (Willis et al., 2002) and these data have been used in multiple population studies. Scott, Brown, Darlow, Forbes and Moore (1992) found that between 1982 and 1990 prevalence of T1D increased from 100/100,000 to 115/100,000 individuals aged 0–19 years. Furthermore, they found that although incidence increased over time, it did so in a series of peaks and troughs lasting two to three years (Scott et al., 1992), as reported later by Willis et al. (2002). Scott et al. (1992) caution that due to the cyclical nature of increases and decreases in incidence, possibly due to environmental factors, it is necessary to use longitudinal methods to ascertain whether short-term fluctuations are representative of a long-term change in incidence.

In their prospective longitudinal study of children and adolescents in Canterbury, Willis et al. (2002) studied the incidence of T1D diagnosed before age 20 years in Canterbury between 1970 and 1999. Cases diagnosed before 1982 were added retrospectively from

hospital and GP records. Willis et al. (2002) found that over the 30 year period, the incidence in this population increased 3.4 times per 100,000 person years. The authors found that the increase was not only consistent with other international studies suggesting an increased incidence rate of T1D, but that Canterbury had become a high risk location for the incidence of T1D for the population aged between 0–19 years over this period. In a later study, Willis et al. (2008) analysed prospective incident cases of T1D diagnosed in children and adolescents under 15 year olds between 1980–2004 and found that incidence had increased at a rate of 5% per annum. Over this period, the authors found that 337 new cases of T1D were diagnosed in the Canterbury region for 0–14 year olds, and children were diagnosed at a mean age of 8.79 years.

Miller et al. (2011) used the data from the Canterbury Register to ascertain whether there was a geographical distinction in new incident cases of T1D reported in Canterbury. The authors found that incidence was higher from satellite urban communities than main urban areas or rural areas for the population size. One possible reason given by the authors for the increased rate of incidence is the hygiene principle, because in satellite urban communities, children were likely to receive less exposure to different people than in urban areas and less exposure to animals than in rural areas (Miller et al. 2009; Miller et al, 2011).

Another local study by Obaid, Britt, Wallace-Bell and Johnson-Elsmore (2012) sought to update the data held for youth with T1D in Canterbury with differing results. Obaid et al. (2012) found that although prevalence had increased in Canterbury by 12% for 15–24 year olds over the period between 2003 and 2010, this was not a significant increase. Although the increased prevalence was not statistically significant, there was an overall increase in the total number of young people in Canterbury with T1D since 2003 (Obaid et al., 2012).

Rationale for Study

As incident cases of T1D and the burden of care continue to increase, successful self-management of T1D becomes increasingly important. Self-management of T1D, which includes keeping blood glucose levels within a narrow range, is necessary to maintain quality of life in the present and prevent complications from arising in the future. In childhood, management is mainly carried out by parent(s) but during adolescence this responsibility is transferred to the adolescent and by adulthood, management is fully carried out by the person with the condition. As will be shown in the following chapter, exercise management is one of the areas of diabetes treatment where there has been relatively less research. Incorporating regular exercise into daily or weekly routines as part of a healthy lifestyle is not only a task for adolescents with T1D but also for typically developing adolescents.

The purpose of the research is to learn about the process of young people with T1D learning to take responsibility for managing their exercise as part of their diabetes self-care routine, and to examine this in the context of typical adolescent development. This study aims to explore exercise as an aspect of diabetes management throughout adolescence. In general, it aims to learn more about the process of how young people with a chronic disease take responsibility for self-management of their exercise during adolescence, and how this relates to the development of autonomy during adolescence. Specifically, it also aims to learn more about the lived experiences of young people with T1D regarding their exercise behaviours throughout adolescence, and when and how the responsibility for maintaining regular exercise transferred from being parent-led to adolescent-led.

Conclusion

Because permanent treatments are experimental and may not be appropriate for all people with T1D, current best practice relies on symptom management. This includes tasks such as blood glucose checking, insulin administration, and regulation of diet and exercise.

The ability to self-manage diabetes is crucial, because T1D is a non-preventable, lifelong condition which not only has negative short-term effects, but if left unmanaged it is likely to lead to major long-term complications and death. Therefore it is important to learn as much as possible about how adolescents with T1D negotiate the transfer of responsibility for successful diabetes management into adulthood to mitigate future negative consequences.

The next chapter will indicate the scope of the study and review the literature on T1D, adolescence, autonomy development and exercise/physical activity. The following chapter will describe the methods used in the study, followed by a chapter describing the results of the study. The final chapter will discuss the results of the study in the context of the literature and the implications of the research to the lives of adolescents and emerging adults with T1D.

Chapter 2

Review of the Literature

Introduction

This chapter will present an overview of previous research on diabetes management in adolescents. It will also consider aspects related to diabetes management including factors affecting the transfer of responsibility from parents to adolescents, the development of exercise behaviours in typically developing adolescents, and the development of autonomy in adolescents.

A literature search was performed via the following databases: Google scholar, PsycINFO and a MultiSearch function searching multiple databases by the University of Canterbury library. Further articles were found via the references from previously obtained articles. Terms searched for included: Type 1 diabetes; adolescence; autonomy; transfer of responsibility; self-management; self-care; adherence; exercise; physical activity; qualitative research; and combinations of these terms. Searches were limited to publications in the English language.

Terminology: Adherence, Self-care and Self-Management

Formerly, the term “compliance” was used to describe patients’ self-care behaviours. The use of this term fell out of favour because it implied that patients needed to follow a regimen prescribed by a doctor as the authority figure. More recent research has shown that to be successful, diabetes management plans need to be developed in collaboration with the patient, taking into consideration their personal goals and motivations for behavioural change (Wolpert & Anderson, 2001). Young adults (aged 18–35) with T1D in Australia have been shown to prefer this approach, called “shared decision-making” (Wiley, Westbrook, Greenfield, O Day & Braithwaite, 2014).

La Greca and Bearman (2003) discussed the topic of self-care behaviour to treatment plans in children and adolescents, and the difficulties in researching the topic of adherence in general. One difficulty was the difference between the management of acute and chronic conditions. Acute conditions generally involved fewer and more quantifiable instructions such as taking a number of pills, while chronic conditions were more complex and involved the consideration of multiple behaviours. In addition, parents needed to weigh their children's health needs against their other developmental needs, including the need to feel normal and accepted (La Greca & Bearman, 2003). Another difficulty was that patients were often given alternative advice for the same condition depending on their individual circumstances, which made it difficult to compare health behaviours directly. La Greca and Bearman (2003) noted that measures of "adherence" often did not measure the individual advice given to a patient, but instead usually measured behaviours against an "ideal" management plan. According to La Greca and Bearman (2003) the term "self-care behaviour" was preferred when patients' behaviour was not compared to an ideal, but was instead considered in terms of general health behaviour.

In the literature surrounding self-care in adolescents with T1D, the concept of taking responsibility for diabetes self-care was often considered by specialists as equivalent to, or an important component of, achieving successful self-management (Hanna and Decker, 2010). For the authors, these concepts needed to be differentiated to clarify common terms used in alternative ways by differing researchers. The authors concluded that the process of taking responsibility for self-care, or autonomy, must be separated from the outcomes of the process, including successful self-management. In a recent publication, Hanna et al. (2013) developed this concept further through a framework for the transition of responsibility, and identified three main outcomes desired as a result of the transition: health outcomes, or diabetes-related quality of life; developmental outcomes, with the adolescent taking primary diabetes care

responsibility and ownership of their condition and treatment; and behavioural outcomes, which involved successful diabetes management leading to blood glucose control.

However, the majority of the literature for chronic illness continues to use the terms “diabetes management”, “self-management” or “self-care” to describe the health care behaviours of people with diabetes (Furler, Harris & Rogers, 2011; Schilling, Grey & Knafl, 2002b). In their publication “National Standards for Diabetes Self-Management Education”, the A.D.A. used the terminology “diabetes self-management education” to refer to “the ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care” (Funnell et al., 2009, S87). This study will generally use the terms “self-care” and “self-management” to describe healthcare behaviours of young people with T1D, and when outcomes refer to blood glucose levels they will be named as such.

The Management of Type 1 Diabetes in Young People

During childhood, parents typically take responsibility for managing their child’s diabetes. During adolescence, this gradually shifts towards adolescents taking more responsibility for managing their diabetes-related tasks. As adolescents assume more independence, they begin testing the boundaries of both their physical limits and of parental influence (Timms & Lowes, 1999). In many cultures, this is a developmentally normative process as adolescents begin to individuate from their parents and find their own identity (Steinberg & Morris, 2001). However in terms of treatment, the demands of strict adherence to a diabetes treatment plan may conflict with the developmental tasks of adolescence, increasing the stress placed on adolescents and their parents (Kyngäs, Hentinen & Barlow, 1998; Silverstein et al., 2005). Adolescents are generally working towards achieving success in domains such as peer friendships, academic work, conduct, employment, and romantic relationships (Roisman, Masten, Coatsworth & Tellegen, 2004).

Key developmental issues that need to be taken into account in terms of T1D for adolescents include: the importance of belonging to a peer group, exploration of alternative lifestyles, experimentation with tobacco, drugs and alcohol, increased independence from parents, increased academic pressure, beginning to earn money, and changing patterns of sleep and exercise (Court, Cameron, Berg-Kelly & Swift, 2008). Brink and Moltz (1999) analysed data from the DCCT (1993) and found common situations with the potential to be problematic for adolescents include decisions about whether to sleep in, identifying themselves to others as having diabetes, what and how much to eat, driving and sport and exercise. Therefore the management of T1D in adolescence requires a different approach from that of either children or adults.

Blood glucose control generally worsens during adolescence (Court et al., 2008; Dabadghao, Vidmar & Cameron, 2001; La Greca, Follansbee & Skyler, 1990). This is due to a number of factors, including an increase in irregular mealtimes and exercise, decreased adherence to treatment plans, increased high-risk behaviours, and an increase in the incidence of eating disorders (Court et al., 2008). Additionally, neurological, hormonal and physiological changes lead to differences in the way that insulin is processed in adolescence, leading to both an increase in the amount of insulin needed and to reduced treatment adherence (Cameron, Northam, Ambler & Daneman, 2007; Court et al., 2008). There is also a positive association between increasing age and length of time since diagnosis and worsening blood glucose levels (Greening, Stoppelbein, Konishi, Sytsma Jordan & Moll, 2007). Even for adolescents who adhere closely to treatment plans, blood glucose control tends to worsen during adolescence due to the natural insulin resistance associated with puberty, particularly for girls (Moran et al., 1999).

Adolescents' cognitive development may also interfere with diabetes self-management by affecting decision-making processes. Adolescents are known to be more

susceptible to immediate than to long-term rewards (Steinberg, 2010). Additionally, Palardy, Greening, Ott, Holderby and Atchison (1998) found that diabetes self-management in adolescents with T1D was more likely to be influenced by the perceived response cost of performing self-care tasks than by the rewards of either performing or not performing self-care tasks. Adolescents may also have a heightened sense of invulnerability (Romer, 2010) leading them to believe that long-term complications will not happen to them.

For adolescents, being accepted as part of a peer group, and the fear of being identified as different (Salamon, Hains, Fleischmann, Davies & Kichler, 2010) may mean that adolescents with T1D are less likely to perform diabetes tasks around their peers. Despite the fact that better blood glucose control is associated with improved quality of life for adolescents and their families (Hoey et al., 2001), adolescents may perceive that the short-term costs of diabetes self-care tasks outweigh the potential long-term benefits of future health. Peer support, however, is also known to encourage diabetes self-management in adolescents (Pendley et al., 2002) and has been linked to improved blood glucose levels. Skinner, John and Hampson (2000) also found that peer and family support predicted levels of self-management and well-being.

The Self-Management of Type 1 Diabetes in Emerging Adulthood

Emerging adulthood is a period of life between ages 16–25 years, which is an intermediate period between adolescence and young adulthood (Arnett, 2000; 2006). In New Zealand, this coincides with the maximum age that someone can be considered a “youth” or “young person”, this being 24 years according to the New Zealand Ministry of Youth Development (2012). Emerging adulthood is characterised by a relative lack of both dependence and responsibility, and is a time when young people may explore multiple possibilities for their future life directions, including careers, close relationships and ways of seeing the world (Arnett, 2000). Emerging adulthood is possible in industrialised countries

where young people are able to delay making enduring commitments to not only demographic changes such as marriage, children, study and careers, but also to identity development tasks such as taking responsibility for themselves and independent decision-making (Arnett, 2000). During this time, young people are typically transitioning from attending school to employment or further education/training, and this may coincide with the young person leaving the family home (Arnett, 2000).

Even after adolescence, the living situation of emerging adults continues to influence diabetes self-management. Hanna et al. (2013) studied responsibility for diabetes care in emerging adults (aged 17–19) in the U.S.A. when they were in their final six months of high school and at follow up six months afterwards. The authors found that emerging adults took more responsibility for their diabetes care after leaving high school regardless of whether they subsequently moved away from home or remained living with their parents. Hanna et al. (2013) also found that for emerging adults with low diabetes self-efficacy, remaining at home predicted higher diabetes responsibility, while for those with high self-efficacy, moving away from home predicted higher responsibility. Additionally, Hanna et al. (2013) found higher responsibility for females than males after moving away. Young people's confidence in their ability to manage their diabetes may therefore have wide-ranging effects, including effects on their readiness to move away from the parental home.

For young people, diabetes self-management can also be predicted by their perception of T1D and the extent to which they believe that they can manage its effects on their lives. A U.K. study of adolescents and emerging adults (aged 15–25) with T1D demonstrated that self-efficacy was associated with perceptions of diabetes, particularly aspects relating to “control”, “identity” and “consequences” (Griva, Myers & Stanton Newman, 2000). The authors also found that young people's beliefs about “control” were linked to closer adherence to medical advice. As Griva et al. (2000) have shown, young people who believe

that they can successfully self-manage their diabetes are more likely to translate this into health behaviours.

Importance of Establishing Responsibility for Self-Management in Adolescence

During adolescence, parents typically encourage teenagers to take on more of the responsibility for taking care of themselves and their diabetes management tasks, and most adolescents are also motivated to become more independent from their parents. However, diabetes self-management is a complex and challenging task, and learning how to manage all the factors involved takes time and experience. Adolescence is considered to be a critical stage in developing diabetes self-management skills for adulthood (Holmbeck, 2002; Williams, Holmbeck & Greenley, 2002), therefore improving adolescents' diabetes self-management during this period is likely to have lasting benefits.

Because elevated levels of blood glucose are known to lead to long-term complications in later years, poor diabetes management during the adolescent years may have lasting and irreversible effects (Silverstein et al., 2005). At a seven-year follow-up to the Diabetes Control and Complications Trial Research Group (DCCT) trial, the Epidemiology of Diabetes Interventions and Complications (EDIC) study (2000) found that patients who maintained near-normal blood glucose for an average of six and a half years during the DCCT trial had fewer long-term complications than those who had elevated blood glucose levels during this time (Nathan et al., 2005). Even small reductions in blood glucose levels towards normal levels were linked to a reduction in the risk of future complications, which means that any small improvements in blood glucose levels made during adolescence may potentially have a strong impact on future quality of life (Nathan et al., 2005).

Although adolescents will ideally learn to self-manage their diabetes, it is important that responsibility for self-management is appropriate for the adolescent's stage of development. Parents may believe that once their children reach adolescence, they will be

able to manage their diabetes alone, and consequently withdraw their supervision. However, more recent research suggests that adolescents should not be expected to take full responsibility for individually managing their diabetes (Silverstein et al., 2005). If parental supervision is withdrawn too early, adolescents are less likely to adhere to their diabetes management plan, and blood glucose control is likely to worsen (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997; Anderson et al. 2009; Silverstein et al., 2005). Instead, responsibility for diabetes care should ideally be shared by the family, with the aim of a gradual transition of responsibility from parents to adolescent (Court et al., 2008). Introducing a complex management plan and expecting adolescents to take sole responsibility before they are ready may lead to them feeling overwhelmed by the magnitude and never-ending nature of the task, resulting in less self-care (Madsen, Roisman & Collins, 2002).

Transfer of Responsibility in Other Chronic Conditions

Newbould, Smith and Francis (2008) investigated the transfer of responsibility for medication from parents of adolescents with either asthma or T1D in a qualitative study which included separate interviews with 69 children and adolescents (aged 8–15) and with their parents in the U.K. The authors found that factors thought to assist the transfer of responsibility included increasing independence through nights spent away from home with friends or school, the ease of administering medication effectively, and the milestone of attending high school. Factors thought to hinder the transfer of responsibility included the deterioration of the adolescent's health, and conflict between parents (Newbould et al., 2008). Newbould et al. (2008) found that of the 69 parents interviewed, only four had asked clinicians for advice about the transfer of responsibility, and only one parent had felt reassured by the answer received. This study highlights the need for improved knowledge about the role of the transition process to parents, adolescents, and health professionals.

Factors Affecting Self-Management and the Transfer of Responsibility in T1D

The factors affecting diabetes self-management are complex and interrelated, while there are conflicting accounts of the most salient factors in the literature. An early study by Miller-Johnson et al. (1994) studied factors thought to predict self-management in children and adolescents (aged 8–18) in the U.S.A. and found that the only significant predictor of self-management and blood glucose control was family conflict. In another study from the U.S.A, Laffel et al. (2003a) found that diabetes-specific family conflict was more predictive of unsuccessful diabetes management than non-diabetes related family conflict. In particular, the frequency of agreement and discordance over whether the parent or child should take responsibility for certain tasks was linked to blood glucose control (Laffel et al., 2003a).

In their review article, Anderson and McKay (2011) found that there were five major barriers to improvements in metabolic control for adolescents with T1D: developmental issues, psychological issues, family factors, transition issues and socio-economic status along with cultural issues. Similarly, Glasgow, Toobert and Gillette (2001) investigated the wider psychosocial factors affecting diabetes self-management. They found that low self-efficacy and low family support were two of the key barriers to both quality of life and successful diabetes management.

Lewin et al. (2006) found that both diabetes management and family functioning were linked to blood glucose levels, with adherence to a diabetes management plan mediating the link between family functioning and blood glucose levels in children. This further underlines the importance of family functioning on health outcomes for children and adolescents with T1D. A study of children and adolescents (aged 10–15) in the U.S.A. by Palmer et al. (2004) found that other factors affecting the transition of diabetes management included age, maturity level, gender and family factors. Likewise, Anderson and Wolpert (2004) studied the self-management of T1D in adolescents in a developmental context. They noted that

adolescents face challenges in multiple domains at this time, and that the transition of diabetes care must take into account the adolescent's readiness to accept responsibility.

Developmental Issues Regarding the Transfer of Responsibility in Adolescence

Components of self-management. Diabetes self-management is a complex balancing act that requires the adjustment of multiple variables in order to mimic the action of the pancreas in maintaining near-normal blood glucose levels (Coffen, 2009). Because diabetes is a disorder of metabolism, there are many reasons why the insulin administration may need adjusting. Examples include factors such as body temperature, the body part being injected (Robertson, Adolfsson, Riddell, Schiener & Hanas, 2009), dehydration levels, time of day that exercise occurs and even experiencing an emotion such as excitement (Maahs et al., 2009).

In their review, Borus and Laffel (2010) note that self-management is particularly difficult for adolescents as this period combines the physical changes of puberty with barriers to treatment adherence. These include typical behaviours associated with adolescence such as risk taking, anxiety about peer opinion and acceptance, a desire for conformity, self-care "burnout" caused by the constant and long-term vigilance required to live with such a chronic illness, and increased self-care responsibility without a full appreciation of tasks and likely outcomes (Borus and Laffel, 2010). Lancaster et al. (2010) found that some of the main self-reported barriers to tight glycaemic control for adolescents and emerging adults were family conflict, symptoms of internalising disorders, and not closely following medical advice given to them. Specifically, participants reported that they did not perform diabetes management tasks when the timing was inconvenient or they had failed to plan ahead, for example, by bringing their testing kit along with them during activities. Participants also reported that the most challenging diabetes-related task reported was the technique of carbohydrate counting,

or estimating the number of carbohydrates in the meal they were about to eat (Lancaster et al., 2010).

Schilling, Grey and Knafl (2002a) analysed the concept of self-management in diabetes and identified 42 separate skills or behaviours associated with the daily treatment regimen for T1D. The authors found that these fell into the categories of a process, an activity or a goal, with the majority falling into the category of an activity. These ranged from relatively simple, such as “practising good hygiene” to relatively complex, such as “recognise threats to psychosocial adjustment and respond” (Schilling, Grey and Knafl (2002a). As different skills and behaviours require varying amounts of cognitive and emotional development, it is clear that adolescents are able to take responsibility for some tasks earlier than others, for which parental supervision remains needed.

Coffen (2009) performed a comprehensive analysis of daily and nondaily diabetes self-management tasks, and identified over 600 individual cognitive and behavioural tasks that were summarised under general aspect of diabetes care. He noted that when tasks that appeared simple such as “injecting insulin” were broken down into many smaller constituent tasks, they were actually much more complex than they initially appeared. Coffen (2009) emphasised that healthcare teams which did not fully appreciate the complexity of the task of self-management would not be able to convey it to the adolescent, who might believe that they were performing self-care behaviours as instructed but then failed to achieve satisfactory blood glucose control. According to Coffen (2009), adolescents’ failure to successfully self-manage their diabetes may be considered by adults to be deliberate defiance, when in fact the adolescent may have felt overwhelmed, have understood only part of an instruction or have forgotten what they were supposed to do. Coffen (2009) concluded that for healthcare teams, it is important that they modify their expectations, review adolescents’ diabetes knowledge

periodically, and ensure that the transition of responsibility for self-management occurs gradually and under supervision.

There have been conflicting views about the age that adolescents become able to manage each of these behaviours independently from their parents, possibly due to individual differences (Coffen, 2009). Earlier studies found that different members of the healthcare team disagreed on the age that adolescents were able to independently master the diabetes management tasks by an average SD of 2.1 years depending on the task (Wysocki, 1990). This meant that adolescents and their parents were likely to receive differing advice depending on the member of the healthcare team with whom they met. More recent literature has confirmed that although children and younger adolescents may have the ability to perform certain tasks, they may lack the maturity and discipline to perform these tasks consistently and independently, and continued parental guidance is therefore required (Silverstein et al., 2005).

Developmental issues for adolescents with T1D. There may be some developmental differences between typically developing adolescents and those with a chronic illness such as T1D, including autonomy development. Seiffge-Krenke (1998) ran a longitudinal study in Germany investigating the perceived developmental status of adolescents with and without T1D. The author developed an instrument using self-report and parent-report measures to assess autonomy development in 11 developmental areas. Seiffge-Krenke (1998) found that for developmental status in areas adolescents reported as already achieved, adolescents with T1D rated themselves as lower on physical maturity and individual lifestyle, but higher on occupational competence than their typically developing peers. In terms of the developmental status that adolescents desired to achieve, adolescents with T1D considered socio-political awareness to be less important than their typically developing peers. Seiffge-Krenke (1998) noted that for adolescents with T1D, the demands of a chronic illness were likely to lead to a

more structured family life, which may account for more negative ratings of perceived achievement of individual lifestyle but more positive ratings of occupational competence. For achieved physical maturity, Seiffge-Krenke (1998) noted that adolescents' self-reports did not agree with maternal reports, and suggested that differences were likely to be due to adolescents' poor body-image. There was little difference between the groups regarding future developmental goals (Seiffge-Krenke, 1998).

Developmental issues in the transfer of responsibility. Research has previously linked premature transfer of diabetes management from parents to adolescents with higher levels of family conflict, poorer adherence and lower glycaemic control (Anderson et al., 1997; Wysocki et al., 1996). More recent research has begun to acknowledge the importance of age and developmental level on adolescents when assessing their self-management levels, and when it is appropriate for parents to assist them with their daily routines. Some reasons given by mothers for the transfer of diabetes monitoring responsibilities to adolescents included age, pubertal status, perceived adolescent competence and reducing family conflict (Palmer et al., 2004). However, when responsibility was given to adolescents with less autonomy and lower pubertal status, Palmer et al. (2004) found that blood glucose levels worsened.

As may be expected, increasing age in adolescents has been linked to an increase in self-responsibility. This was demonstrated by Schilling, Knafl and Grey (2006) who investigated changes in levels of self-management in 22 youth with T1D using categories of preadolescents (aged 8–11), early adolescents (aged 11–15), mid-adolescents (aged 15–17) and late adolescents (aged 17–19) to identify both the division of diabetes-related tasks and the current state of responsibility transfer. The authors found three patterns of diabetes management: parent-dominant, transitional and adolescent-dominant, with levels of adolescent-dominant responsibility increasing as adolescents aged. Schilling et al. (2006) also

found that patterns of conflict changed over time, with the highest levels of conflict in early adolescence around issues of blood glucose monitoring and food, with the next highest levels in mid-adolescence, and exercise becoming the most common cause of conflict. Schilling et al. (2006) conclude that parents should be taught to be observant for signs that their adolescent is ready to assume more responsibility, while preparing for continued monitoring of early adolescents and the likelihood of conflict during this phase of development in particular.

Age. Age is one factor that affects the transition between parent management and adolescent self-management of diabetes. Palmer et al. (2004) found that mothers relinquished more control according to age, but also to pubertal status independent of age, and perceptions of their child's autonomy and competence. La Greca, Follansbee and Skyler (1990) found differences in the diabetes management of preadolescents (aged 7–11) and adolescents (aged 12–17). For preadolescents, successful diabetes management as defined by blood glucose levels were related to mothers' knowledge about diabetes and preadolescents' level of responsibility, with increased responsibility by the preadolescent linked to worse blood glucose control. For adolescents, blood glucose levels were related to adolescents' knowledge about diabetes and their self-care behaviours (La Greca et al., 1990). An earlier study by Shirkfollansbee (1989), however, concluded that age itself was less important than factors such as level of diabetes education, maturity, performance of diabetes tasks, degree of diabetes-related self-efficacy and family factors. Palmer et al. (2009) parental involvement in diabetes tasks decreased with age, but when adolescents felt they struggled to cope with diabetes, maintained parental involvement led to improved blood glucose levels.

A review article by Guo, Whittemore and He (2011) on the link between self-management and blood glucose levels found that 13 years was a key age affecting the transfer of responsibility, because pubertal status changed after this age. The authors reported that

conflict often occurred because adolescents typically sought more autonomy over diabetes management at a time when increased insulin resistance made blood glucose control more difficult and other needs such as peer acceptance often took priority over diabetes management. Guo et al. (2011) also reported that psychological issues, particularly anxiety and depression, were linked to adolescents' ability to successfully take over self-management from their parents.

Due to knowledge gained from the DCCT, there has been a shift in the recommended frequency of insulin therapy from conventional treatment of twice-daily injections to more intensive treatment of four or more injections per day (DCCT Research Group, 1993). More intensive management of T1D is associated with an increased risk of experiencing hypoglycaemia, and because it is more dangerous in younger children, this shift generally takes place once children are over the age of seven years (Mortensen, Hougaard et al., 1997). However, the age that intensive management is introduced may also affect adolescents' psychosocial functioning.

Using information from the DCCT, Madsen et al. (2002) investigated both quality of life and psychiatric symptoms in adolescents with T1D who either stayed with a "conventional" or less intensive treatment, or who had been introduced to an intensive management plan as either younger adolescents (aged 13–15) or older adolescents (aged 16–18). The authors found that for younger adolescents, the introduction of intensive management led to a small increase in the level of school dissatisfaction compared to peers using conventional treatment. For older adolescents, the authors also found a non-significant trend towards increased psychosocial distress with intensive treatment compared to peers using conventional treatment. Madsen et al. (2002) theorised that the intrusiveness of the management plan affected adolescents' experience of school, friendships and close relationships. Additionally, the authors theorised that healthcare professionals' expectations

of perfect blood glucose control during adolescence was not possible, and may be associated with depressive symptoms in adolescents. Madsen et al. (2002) concluded that greater awareness of these issues and increased monitoring of adolescents' psychosocial health was needed by healthcare professionals when introducing an intensive management plan during adolescence.

Cognitive maturity. Cognitive maturity appears to be another factor in successful self-management. In their two-year longitudinal study, King et al. (2011) found that adolescents with poor self-management scored lower on measures of self-reliance and self-control than adolescents with a more typical trajectory of diabetes self-management. Additionally, Kaugars, Kichleer and Alemzadeh (2011) found that both adolescents' and their parents' readiness to change predicted the family's stage of change in the transfer of responsibility. They also found that the more responsibility for diabetes management was accepted by the adolescent, the lower the parenting stress of both mothers and fathers.

Miller et al. (2013) found that maturity increased throughout adolescence which was linked to an increase in levels of diabetes self-management, but not to blood glucose levels. Hill-Briggs (2003) found that problem-solving to overcome barriers was a key feature of successful diabetes self-management, and that there were four aspects to problems-solving: problem-solving skills; problem solving orientation (or personality factors); disease-based knowledge, and; transfer of past experience. However, Briggs (2003) found that an improvement in problem-solving skills does not necessarily lead to an improvement in diabetes self-management.

Although limit-testing boundaries and an increased focus on peer approval is developmentally appropriate for adolescents, it may also be one of the challenges to developing good self-management habits to sustain them throughout adulthood. In an earlier study, Thomas, Petersen and Goldstein (1997) found that when given hypothetical situations

with a choice between pleasing peers and taking care of their diabetes, older adolescents (aged 15–17) made more choices aimed at pleasing peers than aimed at managing their diabetes compared to younger adolescents (aged 11–14) and children (aged 8–10), and that these choices were linked to an improvement in their problem-solving skills. The authors found that adolescents used less “black-and-white” thinking and were able to predict multiple outcomes for their actions compared to children. Additionally, Thomas et al. (1997) noted that adolescents were more likely to test the boundaries of their diabetes self-management, leading to lower adherence, than children.

Sex. One of the factors that may affect diabetes management in adolescence is whether the adolescent is male or female. The literature appears equivocal on this. Williams (1999) found that the sex of the adolescent interacted with maternal diabetes management to produce two different profiles of diabetes management in adolescence, with mothers more closely involved with treatment adherence for their sons than for their daughters. Likewise, in a more recent study, Hanna et al. (2013) found a main effect for sex in their study on diabetes care responsibility in emerging adults, with young women taking more responsibility for their self-care than young men.

As adolescents grow older, they may be more at risk of developing psychological difficulties which impact on their self-management. A study by Wysocki et al. (2000) found that older adolescent females’ blood glucose levels and diabetes self-management were worse than either younger adolescent females or adolescent males in either age group. This may be related to insulin omission, particularly in females (Bryden, Mayou & Peveler, 1999). Insulin omission is a form of purging used by people with T1D to control their weight, also known as “diabulemia” (Haagen, 2011; Jones, Lawson, Daneman, Olmsted & Rodin, 2000). Insulin omission prevents the body from using glucose from the blood therefore leading to weight loss but also to hyperglycaemia, with its associated risks.

A study in the U.S. A. by Korbel, Wiebe, Berg and Palmer (2007) investigated the relationship between sex, age, adherence, blood glucose levels and symptoms of depression in younger adolescents aged 10–15 years. They found that increasing age predicted poorer self-reported adherence, but not blood glucose, in adolescent females. For males, both blood glucose levels and self-reported diabetes management improved with increasing age. Moreover, depression partially mediated the interaction between age and sex for self-management, with higher levels of depression found in older females. Korbel et al. (2007) hypothesised that increased insulin resistance during adolescence in girls (Moran et al., 1999) together with an increased tendency to internalise blame for higher blood glucose levels may be linked to higher rates of depression in females than males with T1D. In these studies, it appears that decreased parental involvement and earlier self-management for adolescent females is correlated with poorer outcomes in terms of blood glucose control. Females may display earlier behavioural autonomy than males, but individual maturity and psychological adjustment may influence whether blood glucose levels are maintained or whether they deteriorate over adolescence.

Increased risk of other adverse outcomes. Adolescence is a particularly high-risk time as children and adolescents with diabetes and their caregivers have higher than usual rates of psychiatric disorders (Cameron et al., 2007; Rubin & Peyrot, 1992). In their review, Cameron et al. (2007) noted that children and adolescents with diabetes, and their families, are likely to experience increased physical and psychosocial stressors as measured by health related quality of life indices, and these stressors are likely to persist throughout the lifetime. The authors reported that children and adolescents with diabetes are likely to have increased rates of internalising and externalising problems, in particular, depression, anxiety and eating disorders (Cameron et al., 2007). The authors found that depression was also linked with

lower adherence to the diabetes treatment regime, which is itself linked to higher rates of HbA1c, a measure of average blood glucose levels over the preceding two to three months.

Cameron et al. (2007) believed that psychological screening should be routine for adolescents with T1D, as symptoms of some internalising disorders may appear to be those of poor glycaemic control, such as lethargy and lack of concentration. In their review, Delamater et al. (2001) also reported that children and adolescents with T1D are more likely to have psychological problems than typically developing peers. As in the previous study, these were found to include internalising and externalising problems, especially adjustment disorders, depression, anxiety and eating disorders. According to Brink and Moltz (1997), adolescents may experience hopelessness if they take on responsibility too soon or experience early failures at self-management. In their large multinational study, Hoey et al. (2001) found a link between worse metabolic control and lower quality of life for both adolescents and their families, although the directionality of the effect could not be confirmed.

Eating disorders appear to be more common in adolescents, especially older female adolescents, although there is conflicting literature on the topic. Jones et al. (2000) studied Canadian adolescent females (aged 12-19) and found that those with T1D had eating disorders at nearly twice the rate of adolescents without T1D. Subclinical disordered eating was also found to be higher in the group with T1D than in those without it (Jones et al., 2000). Another study by Colton, Olmsted, Daneman, Rydall, and Rodin (2004) of Canadian girls (aged 9–14) found that rates of mild eating disorders were higher in those with T1D and recommended that routine screening for these disorders should begin before the onset of puberty. Conversely, in a study of adolescents (aged 11–19) from the U.S.A., Meltzer et al. (2001) found that bulimia was not significantly higher in those with T1D than in typically developing peers. However, bulimia was higher in older females than in younger females or males, and was also correlated with higher body mass index (BMI) and increased duration of

T1D (Meltzer et al., 2001). The risk of developing an eating disorder therefore increases over adolescence, with higher risk for females and for teenagers with higher body mass.

Psychological problems may be linked to an increased risk of problems with neurocognitive functioning in children and adolescents with T1D (Delamater et al., 2001). In particular, children diagnosed with diabetes before 5 years of age, or who often experience hypoglycaemia, appear most vulnerable to developing these problems. These include visual-spatial functioning, poorer attention, lower verbal intelligence, memory dysfunction, slower information processing speeds, worse conceptual reasoning and slower knowledge acquisition (Delamater et al., 2001). These children also had lower reading ability and more school absences than their peers. Moreover, verbal memory and working memory were found to affect frequency of blood glucose testing in adolescents, with lower scores on memory associated with less frequent blood glucose testing (Soutor, Chen, Streisand, Kaplowitz & Holmes, 2004). This may indicate a link between frequent episodes of hypoglycaemia in childhood, impaired memory, and less frequent blood glucose checking in adolescence. Repeated episodes of hypoglycaemia in childhood may therefore predispose these children to adverse neurocognitive outcomes in both the short and long term.

Family conflict. During adolescence, typically developing teenagers gradually turn from their parents to their peers for approval and support, and during this quest for independence and adulthood, adolescents are likely to experience less cohesion in their relationships with their parents (Pendley et al., 2002). Family conflict may arise as the adolescent begins to ask for more responsibility and freedom from parental supervision in multiple domains, including health. Family conflict during adolescence is linked to diabetes outcomes (Wysocki, 1993), with a portion of conflict between adolescents and their parents linked to diabetes self-care behaviours and blood glucose levels (Anderson, 2004; Lewandowski & Drotar, 2007). Palmer et al. (2004) found that some parents were reducing

their involvement in diabetes management to reduce conflict, not because adolescents were able to self-manage their diabetes autonomously.

In a qualitative study in the U.S.A., Mellin, Neumark-Sztainer & Patterson (2004) investigated parent-child conflict through interviews with parents of adolescent females (aged 13–18) with T1D. When parents were asked about their experiences, Mellin et al. (2004) found that three broad themes emerged: the difficulties of parenting, positive points about parenting, and coping strategies utilised by parents. Parents raised concerns about the complexity of managing diabetes together with their daughter, and both diabetes-related and non-related conflict. Coping strategies used by parents included changing their behaviours to accommodate T1D, minimising conflict and reducing diabetes-related anxiety for themselves. Mellin et al. (2004) found that parents were able to recognise positive strategies they used, that most parents reported minimal conflict and/or intimacy with their daughters and that conflict, when it occurred, was often based in parental anxiety. The authors also found that when clinicians discussed parents' experiences with them, parents' diabetes-related anxiety was reduced.

Differing perceptions of whether the adolescent or the parent has responsibility for tasks also predicts conflict. In an earlier study, Anderson, Auslander, Jung, Miller and Santiago (1990) studied the sharing of responsibility for diabetes management between mothers and children, adolescents and emerging adults with T1D (aged 6–21) by individually asking each member of the parent-youth dyad to report which person took responsibility for each diabetes-related task. The authors found that conflicting views about who had responsibility for diabetes management tasks predicted higher blood glucose levels, as did acknowledging that neither parent nor the young person took responsibility for tasks. Additionally, there was a main effect for age where young people took more responsibility for self-care tasks with increasing age, but with lower adherence and higher blood glucose

levels. Anderson et al. (1990) emphasised that communication about responsibility for diabetes-related tasks is necessary during the transition of responsibility from parent to youth. The authors advised healthcare teams to incorporate this into clinic visits, as otherwise it may not occur at home.

Conflict over daily diabetes management tasks was more likely to be found over uncompleted tasks for which the adolescent had taken responsibility (Miller & Drotar, 2003). Leonard, Garwick and Adwan (2005) found that parents' continued involvement in diabetes care was associated with increased conflict for adolescents with poorer blood glucose control than for adolescents with better blood glucose control. Although the ultimate goal is to ensure that adolescents are able to manage their diabetes independently, higher collaboration in diabetes treatment between parents and adolescents has been associated with more favourable health outcomes for adolescents (Wysocki et al., 2009) while lower parental involvement has been associated with poorer health outcomes (Weibe et al., 2010). These studies showed that continued parent involvement predicted better blood glucose levels in adolescents, although this meant they had lower autonomy.

Parental involvement in diabetes management. Family factors, especially parental involvement, are another aspect associated with improved diabetes management in adolescents. During childhood, parents are typically responsible for all of the tasks involved in diabetes care, and during adolescence, teenagers increase their responsibility for their health. However, a lack of involvement in diabetes management from parents is associated with worse self-management by the adolescent and an increase in family conflict. Anderson et al. (2002) found that for both children (8–12) and adolescents (13–17), there was a strong link between blood glucose control, self-management, and diabetes-related family conflict.

Family structure also influences diabetes management, as children and adolescents from single-parent families typically show poorer diabetes care behaviours and less ideal

blood glucose levels than those who come from two-parent families (McBroom & Enriquez, 2009). This may be due to lower levels of social support, as the responsibility for maintaining the child's health after diagnosis is usually accepted by the mother (Anderson, 2004). Many mothers find this very stressful, and psychosocial problems are more common in mothers of children with diabetes, especially soon after diagnosis (Gavin & Wysocki, 2006). Low paternal involvement in diabetes management is associated with poorer maternal coping (Lewandowski & Drotar, 2007) and also poorer self-management for early adolescents (King et al., 2012). Wysocki et al. (2009) found that greater parental involvement was associated with more positive diabetes outcomes, and this effect was increased when both the primary and secondary caregivers assumed responsibility for helping the adolescent manage their diabetes.

Relationships with health providers. Health providers may also influence the self-management of T1D in a variety of ways, including their expectations of blood glucose control, their attitudes towards continued parental involvement in diabetes management as adolescents transitioned from paediatric to parent care, and the level of autonomy support clinicians included in interventions. In a qualitative case study, Buchbinder (2009) found that the adolescent's autonomy was highlighted when discussing difficulties with self-management but not during problem-solving, when the clinician and parent effectively overruled her solutions. Kayser, Cossette and Alderson (2014) recently completed a concept analysis of autonomy-supporting interventions for chronic conditions. The authors found that when demonstrated by clinicians, these fell into five key areas: choice, rationale, empathy, collaboration and strengths. Kayser et al. (2014) suggest that incorporating these elements into clinicians' work with patients will increase perceived autonomy regarding behaviour change leading to improved health outcomes.

Brink and Moltz (1997) noted that the way advice was given to adolescents may affect their psychological health. In their opinion, healthcare teams should avoid focusing on the negative long-term outcomes of poorly-controlled diabetes or the unremitting nature of self-management because this may lead to feelings of despair in adolescents. Instead, clinicians should encourage adolescents to ask questions, discuss any difficulties with diabetes management and celebrate all improvements rather than focusing on ideal blood glucose levels.

Clinicians are also in a position recommend or provide interventions for young people. These may include assertiveness development, problem-solving skills and cognitive-behavioural therapy (Timms & Lowes, 1999). Another intervention is Motivational Interviewing, which facilitates behaviour change by exploring clients' ambivalence about change to help reach their goals (Rollnick & Miller, 1995). Motivational Interviewing has been successfully used with adults with T1D and T2D in Canterbury, New Zealand (Britt & Blampied, 2010) and with adolescents (aged 14–17 years) with T1D in a study in Wales (Channon et al., 2007). Motivational interviewing has also been shown to increase physical activity levels in previously inactive adults in Canterbury (Brinson, Kirk & Hornblow, 2013).

In a study of Finnish adolescents (aged 13-17), Kyngäs and Rissanen (2001) found that social support influenced adherence, with support from nurses being the largest predictor of adherence. Anderson and Wolpert (2004) suggest that for healthcare teams, points to incorporate in their practice include: a discussion on adolescents' expectations about taking responsibility; building rapport with the adolescent, especially if the relationship is new; ensuring that families remain involved in diabetes management; identifying and, where possible, minimising barriers to care; and ensuring that the adolescent's goals and needs are factored into treatment plans.

Another issue affecting adolescents with T1D in some countries is the transition from paediatric to adult care, which may result in changes to familiar health centres, healthcare professionals, types of services provided and changes to health insurance plans, causing additional stress and anxiety to the adolescent (Bowen, Henske & Potter, 2010).

Transitioning to adult services may also fail to consider the continuing involvement of parents in adolescents' diabetes management. Allen, Channon, Lowes, Atwell and Lane (2011) ran a qualitative study on the transition to adult medical care in adolescents and emerging adults (aged 13–21) and the role of maternal involvement in the U.K. The authors found that mothers were more or less excluded from the transition process. Even when there was provision for continued maternal support, some mothers felt unwelcome and reported experiencing a sudden shift from being very involved with their child's diabetes management to being not included or supported at all, particularly once their child turned 16 years old. Allen et al. (2011) concluded that some transition centres failed to recognise that parental involvement in diabetes management continued in some form for many adolescents and emerging adults, and that service provision should reflect this continuing support.

Whether or not adolescents can maintain tight control over blood glucose levels may be influenced by the expectations of their health providers. Some clinicians have set lower treatment goals for children and adolescents from ethnic minority backgrounds, including a higher maximum blood glucose range and less frequent blood glucose testing, than for non-minority children and adolescents (Valenzuela et al., 2011). One New Zealand study conducted by Carter et al. (2008) investigated whether there was a link between ethnicity and deprivation and the outcomes of those diagnosed with T1D. The authors found that New Zealanders of Maori and Pacific Island descent and those who experienced economic deprivation had worse glycaemic control, with more episodes of hypoglycaemia and higher levels of HbA1C. La Greca and Bearman (2001) recommended that interventions for T1D

find a balance by adapting to engage and improve health outcomes of families from ethnic minority backgrounds, while aiming not to overwhelm those unable to cope with the intensive treatment plans required for strict blood glucose control.

Autonomy and Adolescence

Concepts of autonomy. In their study, Steinberg & Silverberg (1986) investigated autonomy in preadolescents and adolescents (aged 10–16) in three areas: emotional autonomy from parents, the ability to withstand peer pressure, and perceived self-reliance. They found that increasing age predicted the amount of emotional autonomy as did sex, with females displaying earlier autonomy development than males. Steinberg & Silverberg (1986) also found that when autonomy was higher, resistance to peer pressure decreased and this was particularly evident for maladaptive behaviour. The authors noted that for adolescents, autonomy did not refer to merely a growth in independence and a reduction in need for parental support, but also an increased reliance on peers for support and approval. However, Ryan and Lynch (1989) argued that emotional autonomy as described by Steinberg & Silverberg (1986) referred to emotional detachment from parents, which was of mixed benefit. According to Ryan and Lynch (1989), personal growth in adolescence was optimal when adolescents continued to access parental support.

Garber and Little (2001) examined the concept of autonomy and noted that while early theorists considered adaptive development to be indicated by adolescents distancing themselves from parents, more recent theorists considered “healthy independence” to occur within supportive relationships with parents. Garber and Little (2001) investigated the relationship between emotional autonomy, family conflict, maternal depression and emotional and behavioural problems in adolescents when adolescents were in eighth grade (mean age=13.5 years) and then one year later. They found that compared to adolescents who were low in emotional autonomy, adolescents who were high in autonomy developed more

emotional and behavioural problems when high levels of family conflict and history of maternal depression were present, and fewer emotional and behavioural problems when they were absent. Garber and Little (2001) concluded that continued parental support is necessary for optimal development as adolescents navigate the challenges of this period of development.

In their more recent review, Zimmer-Gembeck and Collins (2003) stated that there are multiple aspects to autonomy, and that these include behavioural, emotional and cognitive forms. According to the authors, the behavioural aspect describes independent functioning and self-regulation of actions, the emotional component describes separation from parents and a reduced reliance on them, and the cognitive aspect describes independent decision-making without being unduly influenced by others.

Baumrind (2005) explored how parenting styles were related to the development of adolescent autonomy. According to her chapter, parenting styles had two dimensions: “responsiveness”, which included expressions of warmth, a communication style which included giving explanations, and promotion of the adolescent’s autonomy, and “demandingness”, which involved increasing expectations of the adolescent, monitoring and regulation of their behaviour, and confrontation. Baumrind (2005) found that adolescents who received parenting that was high in both responsiveness and demandingness (authoritative parenting), or higher in responsiveness than demandingness, were more competent and had fewer adjustment problems than adolescents who received parenting that was higher in demandingness than responsiveness. Less authoritative parenting was associated with higher family conflict and greater autonomy in adolescents (Baumrind, 2005). Anderson (2004) also found that parenting style was linked to diabetes-related conflict, with authoritative parenting producing less conflict and lower blood glucose levels than authoritarian parenting styles.

Additionally, Baumrind (2005) found that higher family conflict was experienced for issues concerning the personal domain than the prudential or conventional domains.

Adolescents who considered that diabetes-related issues fell under the personal domain, and who rejected parental authority for the personal domain, were less likely to comply with parental direction and more likely to experience family conflict. This is a salient issue for adolescents with T1D, who may feel that health issues fall under the personal domain and therefore reject parents' attempts to assist with diabetes management.

The ability to assume responsibility for self-management is closely associated with the development of autonomy, although there are differing points of view as to how "self-care autonomy" is defined. According to self-determination theory, autonomy includes the concepts of increased independence and self-endorsed functioning (Ryan & Deci, 2000). This requires a change in the relationship between the parents and the adolescent, who begins to make more decisions affecting their life as part of normal lifespan development (Van Petegem, Beyers, Vansteenkiste & Soenens, 2012). Self-determination theory has also been linked to Motivational Interviewing (Markland, Ryan, Tobin & Rollnick, 2005) which is based on similar concepts, including the core concept of autonomy.

Development of autonomy in adolescents with chronic conditions. Autonomy development is especially pertinent for adolescents with chronic conditions. Spear and Kulbok (2004) investigated the link between autonomy and health-related behaviour using a concept analysis. They found five concepts related to autonomy: active, individualised, holistic, contextual and developmental. The authors concluded that health professionals needed to embrace adolescents' need for autonomy in healthcare settings, a perspective also shared by Wiley et al. (2014).

The development of autonomy has been studied in children and adolescents with other chronic conditions. Holmbeck et al. (2002) investigated the relationship between parental

overprotectiveness in typically developing children and children with spina bifida, and found that parental overprotectiveness was associated with lower levels of decision-making autonomy for children of both groups. For children with spina bifida, parental overprotectiveness was associated with lower behavioural autonomy for children, who were then more likely to exhibit externalising behaviours. Holmbeck et al. (2002) conclude that the development of autonomy is especially important for children and young people with chronic conditions, and that if parents prevent the development of autonomy, externalising behaviour may become more prevalent. Given that health behaviours are typically a source of conflict between parents and adolescents with T1D, it appears likely that adolescents who are denied autonomy may reject parental attempts to assist diabetes self-management.

Friedman, Holmbeck, DeLucia, Jandasek and Zebracki (2009) found differences in achieved autonomy in their longitudinal study comparing the development of autonomy in young people with spina bifida and typically developing young people from childhood to mid-adolescence. Friedman et al. (2009) found that although autonomy levels in adolescents with spina bifida increased with age, there was an effect for gender and for cognitive functioning. Overall, less autonomy was achieved for males than for females with less autonomy for lower functioning than higher functioning adolescents with spina bifida, compared to their typically developing peers. Friedman et al. (2009) noted that for adolescents with a chronic condition, slower development of autonomy in adolescence may postpone the successful transfer of responsibility for self-care, and may negatively affect adolescents' view of themselves in comparison with their same-age peers.

Development of autonomy in adolescents with T1D. When parents encourage autonomy development, adolescents with T1D increasingly take responsibility for diabetes management with a corresponding worsening in adherence and blood glucose levels (Butner et al., 2009). Adolescents may desire autonomy and rate themselves as high in self-efficacy;

however, there tends to be a discrepancy when adolescents and their parents rate adolescents' competency on diabetes self-management (Butner et al., 2009). According to Butner et al., (2009), this discrepancy is linked to higher levels of parent psychological well-being. The authors conclude that although the development of autonomy is developmentally normative and beneficial, it is associated with short-term stressors for both parents and adolescents, and poor blood glucose control during this period may have long-lasting effects for adolescents.

Similarly, Miller and Drotar (2003) examined discrepancies in perceptions of maternal and adolescent-rated autonomy over diabetes-related behaviour. They found that when adolescents had more autonomy for performing tasks, this led to greater maternal-rated conflict, especially when adolescents considered that they had more autonomy than their mothers did. The authors also found that autonomy and conflict were correlated with pubertal status, rather than with chronological age, with more autonomy and lower conflict associated with higher pubertal status. They hypothesised that this was due to cognitive and developmental changes associated with the onset of puberty. Miller and Drotar (2003) cautioned that problems with self-management and conflict may arise when adolescents are given more autonomy than they are prepared for developmentally.

In a later study, Miller and Drotar (2007) investigated the way that adolescents (aged 11–17) made decisions, and how this affected their diabetes outcomes and the valence of communication between adolescent and parents. Miller and Drotar (2007) confirmed that increased negative communication between adolescents and parents was associated with worse blood glucose control and found that adolescents' decision-making competence was a mediating factor. Adolescents who used more effective strategies to make decisions had more positive communication with parents and better blood glucose levels than adolescents who used less effective strategies.

Karlsson, Arman and Wikblad (2008) investigated the development of autonomy and self-management in teenagers with T1D in a qualitative phenomenological study.

Adolescents were interviewed and asked to describe their experiences of self-managing their diabetes. Karlsson et al. (2008) identified several themes, including: adolescents “hovering” between taking responsibility for their own self-care or allowing their parents to take responsibility; the increase of self-reliance through the experience of making their own decisions and experiencing success; and the increase of confidence through encouragement from parents, acceptance by friends and collaborative support from their healthcare team. Karlsson et al. (2008) found that adolescents’ “hovering” was likely to cause misunderstandings about responsibility for diabetes management within the family, which was then likely to cause diabetes-related conflict. The authors also considered it critical that adolescents learnt how to manage their diabetes through increasing their diabetes-related knowledge, having the opportunity to make diabetes-related decisions (including complex decisions) and learning from the experience. Karlsson et al. (2008) noted that autonomy was developed through adolescents spending more time with peers and away from the family, which led to opportunities for adolescents to gain experience in problem-solving and making diabetes-related decisions independently of their parents.

For some people with T1D, a health scare may serve as a “wake-up call” prompting autonomy for diabetes management. Another qualitative study investigating the management of transitions in Australian women (aged 20–36) with T1D found that one of their key turning points was waking up in hospital after a hypoglycaemic episode (Rasmussen, O’Connell, Dunning & Cox, 2007). For some women, this was the moment when they realised that they needed to take charge of their diabetes management for themselves, while for other women it was a realisation that changes to some aspects of their diabetes management were needed (Rasmussen et al., 2007).

Although older adolescents may perform the majority of daily diabetes management tasks without assistance, full responsibility for self-care may not be reached until the adolescent has left the family home and has begun to live independently (Hanna et al., 2013). This includes such “non-daily” tasks as making clinic appointments and choosing which issues to raise; monitoring and ordering diabetes supplies; and ensuring that friends and teachers or co-workers are aware of their diabetes and know what to do in an emergency. Hanna et al. (2013) found that diabetes care responsibility was related to both gender and self-perceptions of diabetes self-efficacy, with more responsibility assumed by females and adolescents high in self-efficacy. In addition, although responsibility for self-care increased once adolescents were living independently, the authors found that parents continued to take responsibility for non-daily tasks.

Hanna and Guthrie (2003a) studied the development of behavioural autonomy through both decision making and independent functioning in adolescents (aged 11–18) in the USA. They investigated the role of adolescent autonomy in self-management of daily and nondaily diabetes tasks. The authors found that autonomy was linked to lower blood glucose levels and increased with age. The authors point out that during early and middle adolescence, parent involvement is necessary to maintain blood glucose levels and that an authoritative parenting style is preferred as it both sets boundaries and promotes adolescent autonomy.

Parental support of autonomy. Coyne, Wortman and Lehman (1988) explored autonomy and why those closest to someone in need of support, such as a person with a chronic condition, sometimes became overprotective to the point that their support had negative outcomes. The authors called this “miscarried helping” and used the following definition: “how people involved with a person in distress – particularly those closest to that person – may become emotionally overinvolved, critical and hostile to the distressed person,

and became psychologically distressed themselves” (Coyne et al., 1988, p306). Miscarried helping may occur when a support person is invested in the outcomes of change behaviour of the person with a chronic condition, but when the actual behaviour must be done by the person with the condition. After repeated conflict, the person with the chronic condition may perceive that they must make a choice between performing adaptive behaviours and protecting their autonomy (Coyne et al., 1988). Diabetes-related conflict may also be understood in this way, as adolescents seek to assert their autonomy through resistance to parental reminders about diabetes-related tasks (Harris et al., 2008).

A study by Hanna, Dashiff, Stump and Weaver (2012) investigated how the transfer of diabetes management responsibility from parent to adolescent was linked to the amount of perceived autonomy support from parents, and age of the adolescent. Hanna et al. (2012) studied 89 dyads of adolescents (aged 12–17) with T1D and a parent, and found that greater parent autonomy support was linked to greater shared responsibility. They also found that there were some age effects from early to mid-adolescence, as older adolescents reported less perceived autonomy support than younger adolescents while adolescent age did not affect parent report, and older adolescent age was linked to lower levels of shared responsibility reported for parents but not for adolescents. In other words, as adolescents grew older they perceived less autonomy support from parents than was reported by parents, while parents perceived that they needed to take less responsibility for their adolescent’s care than was reported by the adolescent (Hanna et al., 2012). This may lead to a situation where both the parent and adolescent believe that the other is taking more responsibility for diabetes care behaviour than is happening, leading to a gap in tasks being performed through lack of discussion about changing roles for diabetes management.

Exercise and Physical Activity

Definitions of exercise and physical activity. An additional challenge to research in this area is the use of various terms such as “exercise”, “sports” and “physical activity” used by literature of differing fields such as health research and sports psychology. The Physical Activity Guidelines for Americans (2008) defined the difference between exercise and physical activity as follows: “Exercise is a form of physical activity that is planned, structured, repetitive, and performed with the goal of improving health or fitness. So, although all exercise is physical activity, not all physical activity is exercise.” (Physical Activity Guidelines Advisory Committee, 2008, p7). These definitions will be used throughout.

Two methods of measuring exercise and physical activity in health research.

When studying levels of exercise and physical activity, studies tend to use either self-report methods, or a device to objectively measure movement such as a pedometer or accelerometer. Each method has benefits but may not be completely accurate. New Zealand studies have demonstrated some of these inaccuracies in self-report methods. A study by Boon, Hamlin, Steel and Ross (2008) of 70 adults in Canterbury used two self-report instruments and an accelerometer worn for a week to gather information about participants’ physical activity levels. The authors found that self-reported physical activity was overestimated by an average of approximately 165% when compared to data gained from accelerometer use. Another New Zealand intervention study by Newton, Wiltshire and Elley (2009) sought to use text message prompts and the use of an open pedometer to increase the physical activity levels of adolescents with T1D, then assessed the effectiveness using closed pedometers and self-report measures. The intervention was not found to be effective; however, Newton et al. (2009) found that participants overestimated levels of moderate and vigorous physical

activity compared to pedometer count for adolescents in both the control and experimental groups.

Accelerometer use may also improve accuracy when young people under-report the amount of physical activity performed. Hodgkin, Hamlin, Ross and Peters (2010) studied differences between obesity, calorie intake and physical activity levels in New Zealand children and adolescents (aged 5–15). The authors found that obesity was higher in urban than rural young people, however there were no significant differences between the two groups for self-reported energy intake or physical activity levels. The authors theorised that use of self-report instruments, and differences between urban and rural perceptions of what constitutes physical activity, may have led to underreporting of physical activity levels for rural youth. Hodgkin et al. (2010) noted differences between the results of overseas studies and those of New Zealand studies and theorised that these may be due to differences in the socioeconomic status between rural populations, with lower rates of obesity and higher socioeconomic status in New Zealand rural populations. The findings of Hodgkin et al. (2010) reinforce the need for local research that reflects the New Zealand population.

Although more accurate in some ways, accelerometers are not infallible when it comes to accuracy (Boon et al., 2008). Accelerometers are generally accurate for activities such as running or walking but may underestimate stationary physical activity, such as using an exercycle. Accelerometers are sensitive to where they are located on the body, so a wrist-based model will be subject to more movement than the same model worn at the hip. Models that are not waterproof cannot be worn during watersports or bathing. This means that total activity levels recorded for activities such as these may be underestimated (Boon et al., 2008).

Despite the limitations, there are also benefits to self-report methods including providing clinicians with rapid information. One self-report instrument designed to measure

different aspects of diabetes self-management is the *Summary of Diabetes Self-Care Activities (SDSCA)* (Toobert, Hampson & Glasgow, 2000). The authors found adequate reliability and validity of the current version of the SDSCA over seven studies using the following scales: general diet; specific diet; exercise; blood-glucose testing; medication taking; and foot care. The current version (Toobert et al., 2000) was based on an earlier version of the *SDSCA* by Toobert and Glasgow (1994). The authors found that the instrument was internally consistent, it significantly correlated with other measures of diabetes self-care, and it had predictive validity with outcomes for weight and for both long-term and short-term blood glucose levels (Toobert and Glasgow, 1994). The studies reviewed for the current version of the *SDSCA* included people with both Type 1 and Type 2 diabetes, and the mean ages of participants over the seven studies ranged from 45 to 67 years old (Toobert et al., 2000).

Exercise and physical activity in typically developing adolescents. Sallis, Prochaska and Taylor (2000) reviewed factors associated with increased and decreased participation in physical activity for adolescents (aged 13-18). Factors that correlated with increased physical activity included: sex (male), sibling physical activity levels, ethnicity (white), behavioural intentions, perceived competence, history of physical activity, level of novelty seeking, support from parents and others, opportunities to exercise and participation in community sports. Factors associated with decreased physical activity included: increasing age, depression and the amount of sedentary behaviour outside of school. Sallis et al. (2000) note that the factors contributing to whether physical activity behaviours occur support an ecological model, with some factors falling into a personal context and others falling into an environmental context. The authors conclude that changes to personal factors may be limited, however environmental factors may be targeted for adolescents who currently have low levels of physical activity.

In their review, Hallal, Victoria, Azevedo and Wells (2006) found that physical activity in adolescence affected health related outcomes via four direct pathways: a link between levels of physical activity in adolescence and levels in adulthood; an effect of physical activity in adolescence and adult health; an effect of physical activity in adolescence and adolescent chronic health; and an effect of physical activity during adolescence and adolescent “acute” or short-term health. The review did not assert an optimal level of physical activity in adolescence, noting that different amounts of physical activity were needed to achieve short-term versus long-term benefits, but instead reiterated previous recommendations of 60 minutes per day of moderate to vigorous physical activity per day for healthy adolescents, with additional weight-bearing exercise twice per week (Hallal et al., 2006).

It is important to learn more about how adolescents take responsibility for regular exercise, because levels of physical activity in adolescence have been linked to physical activity levels in adulthood. Graham, Sirard & Neumark-Sztainer (2011) studied 1902 adolescents and were able to predict their future physical activity levels at both five and ten years from their adolescent attitudes towards sport, exercise and fitness. The authors suggest that in addition to increasing physical activity behaviours, targeting attitudes towards physical activity in adolescence may lead to increased physical activity levels in adulthood.

Motivation for exercise and physical activity in typically developing adolescents.

It is also important to understand adolescents’ reasons for continuing with sports and exercise, and why they choose to stop. One area where this has been investigated is in membership of team sports. Ullrich-French and Smith (2009) assessed the continued membership versus dropout rates of typically developing children and adolescents (aged 10–14) in soccer from one year to the next. Although they initially used a self-determination theoretical framework to test their theory, this was not supported and instead they found that

adolescents' perceived competence at soccer was the single largest predictor of continued team membership. Other influences on youths' continued participation included teammate friendship, maternal relationship quality and peer acceptance. Ullrich-French and Smith (2009) noted that extrinsic motivators may also play a part in predicting behaviour and that because adolescents' feelings towards the sport changed over time, it could not be considered a long-term predictor of future team membership.

Physical activity in children and adolescents with chronic conditions has also been the subject of research. Power, Ullrich-French, Steele, Daratha & Bindler (2011) investigated physical activity levels and correlations with motivation, cardiorespiratory fitness and obesity for young adolescents (aged 12–14). They found that intrinsic motivation to exercise was higher for non-obese youths than obese youths, and that this relationship was mediated by fitness level. The authors noted that their findings are consistent with self-determination theory, and caution that adolescents may react with resistance to perceived threats to their autonomy, particularly attempts by adults to control decisions around behaviours that affect the adolescent's lifestyle and recreational time.

Brunet and Sabiston (2011) investigated the correlation between self-reported motivation and physical activity across the adult lifespan in typically developing emerging adults (aged 18-24), adults, and middle age adults. They used a self-determination theoretical framework with a focus on “organismic integration theory”, as described by Ryan and Deci (2000) to study types of motivation regulation, which were on a continuum from most to least autonomous. Brunet and Sabiston (2011) found age differences in motivation and level of physical activity among the different age groups. For young adults, higher levels of physical activity were correlated with the most motivation regulation types associated with the highest levels of autonomy, while lower levels were correlated with external regulation. This means that physical activity was more likely to occur when the person enjoyed the activity for its

own sake, when the person saw the benefit of the activity and when they sought to avoid guilt and increase a sense of self-worth. Conversely, less physical activity could be expected if the person only did it for a reward or to escape punishment (Brunet and Sabiston, 2011).

The findings of Brunet and Sabiston (2011) may have serious implications for young adults with T1D who need to increase their physical activity levels to improve their health, which is clearly an external reason for exercise. However, this could also be considered to be “introjected regulation”, where people perform the activity in order to escape subjective feelings of guilt or to enhance self-esteem. Brunet and Sabiston (2011) suggest that creating an “autonomy supportive environment” is one possible way to enhance chances of long-term success, while another possible way is by increasing intrinsic motivation, or engaging the young adult in an activity that he/she enjoys doing for its own sake. The authors also consider their results to be consistent with basic needs theory, which emphasises the importance of competence, autonomy and relatedness for optimal development. Wilson and Rodgers (2004) also found support for the self-determination theoretical framework in a study that examined motivation for exercise in adolescent and adult females (mean age=20.9, s.d.=2.2). They found that women were more likely to exercise when they perceived autonomy support from friends, and when their motivation to exercise was autonomous, as opposed to motivation from external sources.

Barriers to exercise and physical activity in typically developing adolescents.

Some reasons why typically developing adolescents may terminate regular exercise routines or sports include: levels of intrinsic motivation (Brunet & Sabiston, 2011); perceived competence, BMI and perceived pressure to lose weight (Gillison, Standage & Skevington, 2011); perceived success based on ego-orientation vs. task-orientation (Cervello, Escarti & Guzman, 2007); cardiorespiratory fitness (Power et al., 2011); and peer and coach factors (Ullrich-French & Smith, 2009). Adolescents may experience varying levels of barriers to

exercise and physical activity, including the ability to access safe places to exercise. Babey, Hastert, Yu and Brown (2008) found that proximity to a safe park increased physical activity levels in adolescents who lived in apartments in lower socioeconomic status neighbourhoods, although this effect was unevenly distributed among adolescents of different ethnicities.

There are also barriers to participation in exercise and physical activity for young people in New Zealand, and levels continue to decline. According to Hamlin and Ross (2005), there was a 2.4% decline in the amount of physical activity of 10-25 year olds between 1997 and 2001. Hamlin and Ross (2005) reviewed factors affecting the decline in physical activity of young people, and found that barriers to physical activity included passive forms of travel, an increase in housing density, a reduction in physical education classes and sport at school, increased time spent watching television and playing video games and reduction in household chores due to labour saving devices. Physical activity was also reduced in young people of lower socioeconomic status, for females and for those who were not of Maori or New Zealand European ethnicity.

Another New Zealand study by Richards, Reeder and Darling (2004) found that sports involvement was increased when adolescents were male, received income from a part-time job and took an interest in a higher number of sports. Richards et al. (2004) also noted that there was a gap between expressed interest and participation in sports particularly for females, indicating that there may be more barriers to sports participation for female adolescents. In their qualitative study of Auckland high school students, Hohepa, Schofield and Kolt (2006) found that the main barriers to increased physical activity included lack of opportunities and lack of peer support for physical activity. Other barriers included physical constraints such as: distance, which led to passive transport; lack of time; and for females, the structure of Physical Education (PE) classes. Hohepa et al.'s (2006) suggested strategies to reduce barriers included increasing peer support for physical activity, increasing availability

of equipment and organised activities at school and in neighbourhoods, and changing the structure of PE classes.

Utter, Denny, Robinson, Ameratunga and Watson (2006) investigated physical activity levels in New Zealand youth (aged 13–17). In particular, they studied the influences of social motivation and access to community based recreational facilities. Utter et al. (2006) found that the highest levels of physical activities were found in males, in Maori and New Zealand European adolescents and in higher socioeconomic adolescents. Utter et al. (2006) found that 75% of exercise occurred in groups or teams, and that physical activity decreases over adolescence. When asked to describe why they exercised, males were more likely to cite enjoyment while females were more likely to cite fitness. The authors conclude that exercise should be promoted as a social activity for adolescents, while the availability of safe venues within their neighbourhoods would benefit those, particularly females, with concerns about neighbourhood safety.

Prapavessis, Maddison and Brading (2004) investigated determinants of exercise behaviours in 3972 adolescents (aged 14–19) in New Zealand. The authors investigated the relationships between self-efficacy, adolescents' readiness to start exercising and the valence of deciding factors (pros or cons) and how these affected exercise behaviours in adolescents. The authors found that self-efficacy and “pros” were positively correlated with readiness to change while cons were negatively correlated. At six-month follow up with 1434 adolescents (aged 14–19) Maddison and Prapavessis (2006) concluded that self-efficacy both increased the likelihood of exercise occurring and was itself increased by exercise. Maddison and Prapavessis (2006) also concluded there was little difference in readiness to change and self-efficacy over the six-month period, and that past exercise behaviours were a key influence on future behaviours.

Exercise and Type 1 diabetes

Exercise and physical activity as one of the key T1D self-care behaviours. Regular physical activity is one of the central diabetes-related health behaviours necessary to maintain optimal health (Maahs et al., 2009; Toni, Reali, Barni, Lenzi & Festini, 2006). Exercise is valuable for people with diabetes as it is associated with improved cardiovascular fitness, reduced weight, reduced risk of developing complications and an improvement in mood (American Association of Diabetes Educators (AADE), 2012; Robertson, Adolfsson, Scheiner, Hanas & Riddell, 2009). It is also associated with lowered risk of mortality, lowered risk of cardiovascular disease and an improved quality of life (Chimen et al., 2012; Tieleman et al., 2013). Daily physical activity that is incorporated into the patient's routine is preferable and regular exercise sessions may also increase insulin sensitivity in the body, leading to lower requirements for insulin over time (Robertson et al., 2009).

Challenges of exercise in T1D. Although recommended for people with Type 1 diabetes, exercise can cause problems in people with T1D due to a lack of blood glucose control, namely hypoglycaemia (including delayed hypoglycaemia) and hyperglycaemia (Maahs et al., 2009; Riddell & Perkins, 2006; Robertson, Adolfsson, Schneiner, Hanas & Riddell, 2009). Aerobic exercise can cause hypoglycaemia and either glucose and/or insulin levels need to be adjusted for exercise longer than 30 minutes (Robertson et al., 2009). Hypoglycaemia may also have delayed onset, and post-exercise blood glucose monitoring is advised (Maahs et al., 2009). The timing and amount of carbohydrates and insulin taken affects the body's metabolism, and the injection site can also affect insulin absorption, as can changes in body temperature.

In their report, Maahs et al. (2009) expanded on issues around exercise for people with T1D because of physiological differences in metabolism during exercise and their need for externally-produced insulin. People with T1D are more likely to experience

hypoglycaemia during or after exercise caused by insulin inhibiting the normal actions of the body during exercise. This includes glucose release from the liver, the breakdown of body fat as a fuel, hormone production from the pancreas and various other areas, and so forth.

Exercise can also increase general sensitivity to insulin, in addition to extra sensitivity at the injection site, and affect glucose transport. Delayed hypoglycaemia may occur 6 to 15 hours after exercise, and may occur while the adolescent is asleep and less likely to wake due to diminished sympathetic nervous system reactivity. Exercise should not be undertaken if blood glucose levels are low (Maahs et al., 2009; Robertson et al., 2009).

Anaerobic exercise, on the other hand, is associated with hyperglycaemia (Maahs et al., 2009). Exercise, especially vigorous exercise, can be dangerous for some people with T1D. If the patient has high blood glucose levels (hyperglycaemia) and ketones are present in the urine, vigorous exercise can make ketosis worse and should therefore be delayed until ketones are no longer present (A.D.A., 2012b). If someone with T1D has already developed complications such as retinopathy or neuropathy, some types of exercise should be avoided. These are generally activities that raise blood pressure, including vigorous exercise and weight bearing exercise such as dancing or running (Robertson et al. 2009). Foot care is important, as foot ulcers are more likely to occur in people with T1D, and feet should therefore be checked for damage after exercise (A.D.A., 2012b).

Hyperglycaemia is also caused by failing to take enough insulin before exercise, due to high levels of glucose released from the liver, inefficient use of glucose by muscle tissue and the breakdown of body fat (Maahs et al., 2009). Dehydration also worsens the effects of hyperglycaemia. According to the International Society of Paediatric and Adolescent Diabetes (Robertson et al., 2009) vigorous exercise should be undertaken with care when blood glucose levels are high, and should not be undertaken at all when ketones are present.

The way that physical activity is structured can also alter the way that glucose is processed, as vigorous exercise is associated with hyperglycaemia and moderate exercise is associated with hypoglycaemia. Exercise that includes periods of intermittent vigorous activity may lead to a slower and more regular decline in glucose levels than sustained moderate exercise (Maahs et al., 2009). New developments such as fast-acting insulin and long-duration basal insulin designed to have minimal peaks may also help to reduce the chance of developing hypoglycaemia during sleep, as does CSII. Maahs et al. (2009) also noted that continuous blood monitoring devices are also able to indicate rising and falling blood glucose trends, but are not yet accurate enough to replace blood glucose testing.

People with T1D have extra challenges to remaining physically active, including the need to check blood glucose and adjust insulin before, during and after physical activity and to stay hydrated before and during exercise (Riddell & Perkins, 2006). Ensuring a proper warm up and warm down is also particularly important for those with T1D (Maahs et al., 2009). For otherwise healthy adults without diabetes complications, endurance events such as marathons are possible (Gallen, 2003), however, this may require supervision by a healthcare team (Devadoss, Kennedy & Herbold, 2011).

Adults with T1D also experience barriers to exercise. A qualitative study in the U.K. by Lascar et al. (2014) found that barriers included: lack of opportunity to exercise; lack of equipment, space or facilities to exercise; insufficient motivation; sense of shame about body size when exercising; poor weather restricting activities, and; lack of education about exercising with T1D. Lascar et al. (2014) found that reasons given by participants to exercise included: health benefits; weight loss; intrinsic enjoyment; and social benefits. Other barrier-reducers, or “facilitators”, to exercise included: subsidised entry to pools and gyms; assistance with time management; and motivation and medical advice about exercising with T1D (Lascar et al., 2014). This study emphasises the need for continued diabetes education

and support from clinicians, even in adulthood, to ensure successful self-management of exercise.

Perceptions of the usefulness of exercise also influences whether or not it is performed. Broadbent, Donkin and Stroh (2011) found that adults with T1D and T2D felt that insulin was most effective at controlling their diabetes, followed by diet, then exercise. Those who were more adherent to exercise regimes also felt they had more control over diabetes and had stronger beliefs that exercise would be helpful in managing their diabetes. The study demonstrated that people's beliefs about the usefulness of exercise affect exercise behaviours, and that interventions that change people's perceptions about exercise will increase adherence (Broadbent et al., 2011).

Exercise and physical activity in adults with T1D. While many sources agree that exercise is both necessary and beneficial to adults with T1D, there does not appear to be a single, worldwide standard in terms of frequency, duration and intensity of exercise or physical activity. A review by Chimen et al. (2012) pointed out that the majority of advice about exercise and physical activity in the literature is directed at patients with T2D, as is most of the evidence regarding their benefits. Chimen et al. (2012) found that although regular physical activity was recommended in the literature, there was no clear advice of the type, intensity and duration of exercise needed. For example, the publication "Position Statement: Physical Activity/Exercise and Diabetes" (A.D.A., 2004) provided only general guidelines about exercise and physical activity, and did not provide specific recommendations on the frequency, duration and intensity of exercise for people with T1D, although recommendations were made for people with T2D.

Similarly, the Australian publication "National evidence-based clinical care guidelines for T1D in children, adolescents and adults" by the Australian Government Department of Health and Ageing specified in the chapter on physical activity, that "no

recommendations or practice points are made” (Craig et al., 2011, p90). Instead, it is recommended that patients are thoroughly screened for the onset of complications before an individualised exercise programme is developed in collaboration between the patient and the medical team (Craig et al., 2011). This individualised programme should take into account the patient’s current level of health, cardiovascular fitness and desired fitness goals (A.D.A., 2004; Craig et al., 2011).

Where specific guidelines are given, they echo general advice given to adults without chronic conditions. For example, in their Position Statement on Diabetes and Physical Activity, the American Association of Diabetes Educators (AADE) (2012) mentioned type, intensity and duration of physical activity only in the conclusion and quoted recommendations for the general public from the publication “Physical Activity and Health: A Report of the Surgeon General” (U.S. Department of Health and Human Services, 1996). The AADE stated these recommendations for Type 1 and Type 2 diabetes. Likewise, in their publication “Position Statement: Standards of Medical Care in Diabetes” (2012b) the A.D.A. guidelines do not specify a difference in exercise between those with Type 1 and Type 2 diabetes, and echo the recommendations of the “2008 Physical Activity Guidelines for Americans” for the general population (U.S. Department of Health and Human Services, 2008). For healthy adults aged 18 or older, the recommendation is for 150 minutes (2.5 hours) per week of moderate exercise per week, or 75 minutes of vigorous exercise per week, or a combination of the two (U.S. Department of Health and Human Services, 2008). Additionally, resistance training to improve strength should be performed on two days per week.

In New Zealand, the Ministry of Health does not provide general guidelines for exercise and physical activity for adults with T1D. Instead, the Ministry of Health recommends that people with T1D receive personalised advice from their medical team

regarding exercise and physical activity (Ministry of Health website, 2014). According to the New Zealand Physical Activity Guidelines (2014) in another section of the website, adults in New Zealand should aim for 30 minutes of moderate intensity physical activity on at least five days per week, where moderate physical activity is defined as the following: “Moderate intensity activity will cause a slight, but noticeable, increase in breath and heart rate. You can still carry on a conversation.” (Ministry of Health website, 2014). However, Diabetes New Zealand does provide specific guidelines on frequency, intensity and duration of exercise and physical activity for adults with T1D. According to the Diabetes New Zealand website (2012), adults with T1D are advised to perform 30 minutes of moderate activity, such as brisk walking, every day (Diabetes New Zealand website, 2012).

Exercise and physical activity in adolescents with T1D. Exercise in adolescents with T1D should be encouraged as it provides multiple benefits, including extending the lifespan through increased cardiovascular fitness, decreased insulin resistance and general wellbeing (Maahs et al., 2009). According to Riddell & Perkins (2006), children and adolescents with T1D should schedule regular light to moderate aerobic exercise to reduce blood glucose, increase endorphins, reduce the risk of long-term complications of diabetes and increase their overall health and fitness.

As with adults who have T1D, there appears to be a lack of consensus for adolescents in terms of specific frequency, duration and intensity of exercise or physical activity. The “A.D.A. Position Statement: Standards of Medical Care in Diabetes” referred only to adult levels of exercise and did not provide any recommendations for children or adolescents (A.D.A., 2012b), nor did the “Position Statement: Physical Activity/Exercise and Diabetes” (A.D.A., 2004). When recommendations were given, they were general recommendations developed for adolescents without T1D. Silverstein et al. (2005) maintained that adolescents with T1D who are otherwise healthy should complete 30-60 minutes daily physical activity

of moderate intensity, stating that these levels were recommended by the Center for Disease Control (CDC) and the American Academy of Sports Medicine (as cited by Silverstein et al., 2005). Maahs et al. (2009) noted that current recommendations for typically developing school-aged youth should receive 60 minutes per day of moderate to vigorous exercise per day (Strong et al., 2005) but they made no comment on whether this is an appropriate goal for children and adolescents with T1D.

The International Society for Pediatric and Adolescent Diabetes (ISPAD) Clinical Practice Consensus Guidelines 2009 Compendium on exercise in children and adolescents with T1D also recommended exercise for this population, but noted that they require close monitoring and have differing reactions to exercise than adults (Robertson et al., 2009). Factors that affect metabolism during exercise include: the type, duration and intensity of the exercise; time of day that exercise is performed; levels of blood glucose; insulin timing, type and choice of injection site (with increased insulin action from limbs and working muscles compared to the trunk); the type and timing of food (especially carbohydrates) taken before exercise; temperature (insulin is better absorbed when the body is hotter); physical fitness level; and even emotion during competition affect how glucose is metabolised by the body during exercise (Robertson et al., 2009).

The guidelines recommended incorporating physical activity into the daily routine, and noted that additional exercise and/or sport will require modifications to the daily routine (Robertson et al., 2009). The authors also advocated good record-keeping of the type and duration of exercise, the amount of carbohydrates and insulin taken before exercise, and blood glucose monitoring at various points before, throughout and after the exercise, to assist in developing a tailored plan around exercise. Training effects should also be monitored, as the amount of exertion (and thus insulin) changes as fitness improves, and as the physical activities themselves change (Robertson et al., 2009). The type of insulin regimen also

influences the level of glycaemic control, with insulin pumps or multi-injection regimens providing the most flexibility and control around exercise. For those undertaking longer duration physical activity, eating more carbohydrates prior to exercise and/or reducing the usual amount of insulin before exercise may result in more stamina and a lower risk of hypoglycaemia. Again, the authors noted that this depends on the individual and their own needs.

It is recommended that children and adolescents with diabetes exercise with another person present (rather than alone), and ensure that others have knowledge of their diabetes, hypoglycaemic symptoms and glucose supplies (Robertson et al., 2009). The guidelines also recommend the use of a medic alert bracelet or similar diabetes identification when exercising. Certain activities such as scuba diving and boxing may be less suitable for people with diabetes due to increased risk of injuries and complications (Robertson et al., 2009).

Because of the risk of hypoglycaemia during and after exercise, and because fear of hypoglycaemia is a serious problem for some adolescents with T1D (Di Battista et al., 2009) it is important that new methods of preventing it are investigated. A Swedish study of children and adolescents (aged 0–18) with T1D who used tight glycaemic control found that hypoglycaemic episodes occurred most often in the spring and most likely were due to increased exercise after winter (Nordfeldt & Ludvigsson, 1999). A study published by the Diabetes Research in Children Network (DirecNet) Study Group (Tansey et al., 2005) on a continuous glucose monitoring system for children found that the devices had acceptable accuracy, but were more accurate at detecting hyperglycaemia than hypoglycaemia. These devices could store information which was later accessed by healthcare teams to identify daily trends in glucose levels and assist in diabetes management planning. Another study published by DirecNet Study Group (Tansey et al., 2006) on the effects of physical activity on blood glucose levels found that 83% of children and adolescents (aged 10–17) with T1D

experienced hypoglycaemia after prolonged moderate aerobic physical activity. They also found that giving a small amount of carbohydrate before exercise was frequently inadequate to prevent hypoglycaemic symptoms for these young people.

A more recent experimental study by Riddell and Milliken (2011) examined the use of real-time continuous glucose monitoring devices to monitor glycaemic levels during physical activity for adolescents with T1D. The devices tracked changes in blood glucose levels every few minutes, therefore displaying a trend of dropping glucose levels.

Adolescents were trained to check the device at breaks and quiet points during exercise, and to take a fast-acting carbohydrate if needed. The authors found that mild biochemical hypoglycaemia occurred twice out of 22 exercise events, and when blood glucose levels were low prior to exercise, mild hypoglycaemia occurred 5 times out of 13 exercise events. Riddell and Milliken (2011) demonstrated that with the continuous glucose monitoring device and low amounts of a rapid-acting carbohydrate, exercise-induced hypoglycaemia may be reduced in adolescents with T1D during and after exercise. The authors conclude that these devices will be a useful tool against hypoglycaemia as they become more prevalent in the community.

Despite these challenges, children and adolescents with T1D can take part in exercise, as long as their diabetes is taken into consideration and monitored. Raile et al. (1999) investigated the amount of exercise and physical activity in German children and adolescents (aged 6–18) with T1D, and found that compared to their typically developing siblings, those with T1D reported both more time spent in sporting activities and higher levels of physical activity outside of organised sports. Raile et al. (1999) hypothesised that the difference was due to either diabetes education on the importance of exercise, or through increased social behaviour through sports for young people with T1D. Conversely, in their cross-sectional study of children and adolescents (aged 6–19) in Italy, Valerio et al. (2007) found that those

with T1D performed less physical activity and had less involvement in sports than their typically developing counterparts. Furthermore, both groups showed a decline in physical activity levels as age increased, with lower levels in females than in males (Valerio et al., 2007). The authors also found a preference for individual rather than team sports in young people with T1D.

Aman et al. (2009) studied physical activity levels in adolescents (aged 11–18) with T1D in an international, multicentre study. Like Valerio et al. (2007), Aman et al. (2009) found that physical activity declined with increasing age and was lower for females than males. Although higher levels of physical activity were associated with improved psychological health, there was no effect on blood glucose levels. The authors also found a link between higher blood glucose levels and adolescents who spent more leisure time on the computer. It is therefore important to understand more about personal motivation for exercise versus other leisure activities, and the factors influencing adolescents' participation.

Role of age in exercise management. It is not yet clear at what age adolescents with T1D are able to take responsibility for independently managing their exercise routine. In typically developing adolescents, physical activity level declines with age throughout adolescence (Kimm et al., 2002; Nader, Bradley, Houts, McRitchie, & O'Brien, 2008) and this pattern is also seen in adolescents with T1D (Valerio et al., 2007). Mackey and Streisand (2008) studied exercise levels in preadolescents with T1D, and found that both parental support and parental conflict about exercise strongly influenced the amount of physical activity performed by the preadolescent. There is evidence that establishing a regular exercise routine autonomously may be a task that is achieved at a later stage of adolescence, due to an association between exercise in adolescence and family support. In their recent experiment to increase exercise levels in adolescents with T1D, Faulkner, Michaliszyn and Hepworth (2010) designed an intervention for 12 sedentary adolescents aged between 12–19 years, and

monitored their exercise and physical activity levels over 16 weeks. At post-test, Faulkner et al. (2010) measured the adolescents' physical activity with activity monitors and found that 45.5% did at least 60 minutes of moderate to vigorous activity per day. The authors found that both attitudes towards exercise and perceived family support for exercise were linked to the amount of exercise undertaken.

Opportunities for Further Research

The role of autonomy has been generally recognised as one of the major factors in the transition of diabetes monitoring behaviours from parents to the adolescent. However, much of the research has focused on blood glucose testing and insulin injections, while the area of exercise in adolescents with T1D appears less researched. As there appears to be little research investigating how autonomy development in adolescents with T1D relates to exercise behaviours in particular, this study aims to fill a gap in the research. Additionally, much of the past research on diabetes self-management has not always taken the developmental differences of adolescents into account when analysing the data. This study aims to study the development of autonomy in exercise behaviours at a year-by-year level, while also considering current levels of diabetes self-care behaviours, developmental status and exercise levels in emerging adults in Canterbury, New Zealand who have completed adolescence.

This chapter has reviewed a number of areas including T1D in adolescence, autonomy development, and self-management of exercise and physical activity. The research is important because the degree to which people with T1D are able to successfully keep their blood glucose within a narrow range has a direct impact on whether or not long-term complications may occur, and exercise is a key diabetes management task. Moreover, a successful transfer of responsibility for T1D management in adolescence is linked to successful self-management of T1D in adulthood. As the incidence of T1D is increasing

around the world and in Canterbury, New Zealand, we can expect that increasing numbers of young people will struggle with the effects of this condition throughout their lives and will need to learn to manage it effectively to prevent complications in later life.

According to Dovey-Pearce, Doherty and May (2007), research on the developmental effects of T1D in adolescence may be relatively lacking “due to the fact it sits between the disciplines of developmental psychology, clinical psychology and health psychology” (Dovey-Pearce et al., 2007, p78). Emerging adults aged between 18–24 years (Arnett, 2000; Arnett, 2006) are of particular interest because they have recently completed adolescence and are typically towards the end of the transition from parent-led diabetes management to self-management. It has been identified that there is limited research in New Zealand on the effects of autonomy development during adolescence and emerging adulthood, and the later self-management of exercise behaviours.

Purpose of the Research

This study seeks to investigate the relationship between the development of autonomy in emerging adults with T1D during adolescence in Canterbury, and the current self-management of their physical activity or exercise routine.

This study will examine participants’ perceptions of their autonomy development throughout adolescence as it relates to exercise, while also considering participants’ current functioning in terms of current diabetes management and levels of exercise and physical activity. This study aims to add to the existing literature in this area, and will incorporate learnings from qualitative research methodology.

Chapter 3

Methodology

Background to the Research and Researcher

My background experiences included times spent as a trainee psychologist and as a youth worker. From personal experience, I knew the sister of a friend who had difficulty self-managing her T1D. The young woman passed out while at the wheel of her car and drove into a wall, then lay in a coma for a year before her death. As a youth worker, my previous role placed an emphasis on non-judgemental listening, prior to providing information and referral to other health professionals. As a psychologist, I was trained to look at narratives in an evaluative way while applying knowledge gained from developmental and ecological psychology perspectives.

The differences between the evaluative approach which I developed during my training and experiences as a psychologist, and the qualitative perspective of this study presented a challenge for me. This study used a qualitative approach which placed the greatest emphasis on participants' lived experiences as described by themselves (Sandelowski, 2000). This meant that I needed to step away from the evaluative part of my training as much as possible so that participants' voices could be heard (Elliott, Fishers & Rennie, 1999). The motivation for this research is to add to the literature in the hope that young people and their families may be spared from experiences such as the one lived by my friend and his family.

Ethical Considerations

The study gained ethical approval from the University of Canterbury Human Ethics Committee (Appendix A). To protect privacy, no information about potential participants was obtained through third parties during the recruitment process. Participants gave informed consent before taking part in the study. Participants' personal information was kept

confidential through use of pseudonyms, removal of identifying detail and use of coding for sports and activities to prevent identification. Additionally, to preserve the anonymity of participants from this small population, information regarding ethnicity and socioeconomic status was not collected. Participants were given the opportunity to check and correct notes made during the interview. These activities are described in more detail later in the chapter.

There are some risks associated with exercise for people with T1D, and this research study did not include a medical professional. To minimise harm, this study was observational and did not attempt to increase participants' exercise behaviours or levels of physical activity beyond what they had been advised to do. The protocol for safety included the provision of a one-page folded information booklet (Appendix A) describing the benefits and potential health issues associated with exercise in people with T1D before participants were asked to wear an activity monitor recording their exercise and physical activity levels. In particular, this booklet provided information describing the effects of exercise and insulin on metabolism, alerted participants to the potential risks of hypoglycaemia and hyperglycaemia associated with exercise and the need for increased vigilance, and also described the benefits and positive health outcomes of exercise. This information was taken directly from a website for people with diabetes in New Zealand and represented best practice at the time of the study (Diabetes New Zealand website, 2012).

One participant indicated that some key diabetes management tasks were not part of her daily routine. She then explained that she was given a diet plan with a standard insulin dosage, as long as she did not perform additional exercise. She felt that she had not been given enough information about diabetes management, exercise and the risk of diabetes complications in the future. At the end of the first meeting, she was given an information sheet regarding diabetes and exercise together with the activity monitor. I met with my supervisor to discuss the appropriate action to take. At the second meeting, I advised the

participant that she should ask her medical team for advice, and also gave her a printout of information about her areas of concern taken from a diabetes website (see Appendix A).

Research design

This study takes a qualitative descriptive approach to collecting and analysing information gathered from participants. Qualitative description seeks to describe events as they occur naturally, with a minimum of influence from pre-established theories or transformation of the data from one state to another (Sandelowski, 2000). It seeks to gain first-hand knowledge of participants' lived experiences and to describe them using low-inference interpretation (Neergaard, Olesen, Andersen & Sondergaard, 2009; Sandelowski, 2000).

This study aims to make sense of participants' current activity levels through exploring their experiences during adolescence. A narrative descriptive approach is appropriate for this study because it seeks to relate participants' current functioning to their perceptions of past experiences. However, it should be noted that the study was necessarily constrained by the boundaries of enquiry because the information sought was predetermined. In addition, I came from a background of psychological research and psychological practitioner enquiry. Therefore, narrative description was used in a pragmatic rather than a strictly qualitative way (Polkinghorne, 2000).

The information gathered about each participant was collated and presented as a case study. According to Baxter and Jack (2008), a case study may be used when the emphasis is on the depth of analysis of a complex topic, when a variety of contexts need to be considered, and when information from multiple sources is required. According to Yin (2009), a case study may be appropriate when any of the following conditions are met: the research question to be answered is a "how" or "why" (rather than a "what") question; the aim is not to alter the behaviour of participants; the context needs to be included as a key influence on the topic, or;

the context and the topic cannot easily be separated (Yin, 2009). As this study investigates the lived experiences of participants and the process of the transfer of responsibility for self-care behaviours, presentation of the information gathered as a case study was considered to be appropriate.

Ensuring Rigour in Qualitative Research

Qualitative research has its own standards for rigour, which differ from those of quantitative research. Qualitative research recognises that each person's subjective experience is both legitimate and unique, depending on the person's prior experiences and context. However, the findings of the research should also be "trustworthy" and meaningful to the people who read them (Lincoln & Guba, 1985). There are multiple models for assessing qualitative research for rigour (Kitto, Chesters & Grbich, 2008; Lincoln & Guba, 1986; Milne & Oberle, 2005; Thomas and Magilvy, 2011). According to Thomas and Magilvy (2011), rigour in qualitative research is focused on four areas: credibility, transferability, dependability and confirmability.

Elliott, Fischer and Rennie (2011) developed another model through identifying 14 guidelines for qualitative research in the field of psychology. Of the guidelines outlined by Elliott et al. (2011), I felt that I successfully achieved rigour in most areas. This includes placing the study in the context of relevant literature and conducting ethical research by the methods described above. Strategies used to enhance rigour in this study included designing an investigative, descriptive study without a preconceived outcome; detailed descriptions of methodology, participants and information collection methods; and open reflection on my own stance as a researcher and practitioner.

I took a self-reflective approach by owning my personal and research stance so that my biases are publicly acknowledged. In this case, I came from a background of developmental psychology with previous experience working with adolescents in a health

setting but with little experience of T1D. This meant that I gained information about T1D via reviewing the literature, which may present a challenge to theoretical validity (Thomas and Magilvy, 2011). One difficulty of performing this research has involved a large amount of literature to be reviewed. Due to the complexity of this issue, literature searches were performed on multiple topics, which led to a large amount of literature being reviewed for the study and may have promoted breadth of coverage at the expense of depth.

I have used quotes so that readers may compare my interpretations with their own. As I selected which fragments of interviews to present, it is possible I could have conveyed meaning not intended by the participant. I sought to avoid this by selecting direct quotes which I believed represented the essence of the participant's intended meaning. I included discrepant data in the results and sought to reduce confirmation bias through designing the study as an investigative, descriptive study, without hypothesising a particular outcome.

I provided credibility checks by asking participants to check my notes from the interview and my pictorial representation of their autonomy for accuracy, in addition to using different methods to obtain information about self-perceived and performed activity levels. I have sought to achieve coherence through presenting information in a narrative format while still preserving details of participants' experiences. I have sought to distinguish between general and specific findings by presenting the results as they apply to participants as case studies, and will outline limits to transferability in the limitations section of the Discussion chapter. I have also sought to present material in a way that is credible and will enhance readers' understanding of the topics being studied.

Participants

Recruitment process. The study used two methods to recruit a convenience sample. Posters (Appendix A) were placed on the Facebook page of Diabetes Youth Canterbury, and on the noticeboards of various tertiary institutions and medical centres in Christchurch. In

addition a snowball method was used. An initial email was sent by the researcher to contacts who then passed the email onto their own contacts, and so on. Potential participants who were interested in finding out more about their current levels of physical activity by taking part in the study then contacted the researcher for more information about the study.

Participants were accepted on a first-come, first-served basis until the maximum number of six was met. Of the six participants who contacted the researcher and attended the first interview, five returned to the second interview. The participant who did not return for the second interview also failed to respond to any subsequent attempts to contact him, therefore his reasons for not completing the study are unknown. This participant was male and aged 19 years.

There were two meetings with participants. Participants who were interested in participating in the study contacted the researcher to arrange an initial face-to-face interview. Potential participants read and discussed the information sheet, and any questions they had were answered. Those who expressed interest in taking part in the study were given a consent form to sign. At the first meeting, self-reported information was collected and the activity monitor was given to participants. At the second meeting, activity monitor information was reviewed and participants were given vouchers to thank them for their time. The interviews are discussed more fully under the procedures section below.

Young people involved in the study. Five young adults (18-24 years) completed this study. Participants were included if they had received a diagnosis of T1D for a minimum of one year, were within the age range of 18-24 years and who lived within the Canterbury region. One year since diagnosis was selected as the minimum length of time to ensure that participants had sufficient time to learn diabetes self-management before taking part in the study. It should be noted that initially the age range of the study was 18-20 years. However there were difficulties in recruitment, possibly owing to the conditions in post-earthquake

Christchurch (recruitment was in 2012), and due to low recruitment numbers, it was decided to extend the upper end of the age range.

The young people who took part in the study are briefly introduced below in ascending order of age. Pseudonyms were used and identifying information was removed or anonymised. This will be described more fully in the data analysis section.

Tess was 18 years old at the time of the study and lived with family members. She was diagnosed with T1D at the age of 16.

Elaine was 22 years old and lived with one other person. She was diagnosed with T1D at the age of 15 and also had a gluten intolerance.

Raewyn was 24 years old and lived with one other person. She was diagnosed with T1D at the age of 22.

Lucy was 24 years old and lived with one other person. She was diagnosed with T1D when she was two years old.

Kelly was 24 years old and lived in a family setting. She was diagnosed with T1D at the age of 12. All participants used multiple daily injections to manage their diabetes.

Setting. The study was conducted at the University of Canterbury in Christchurch, New Zealand, and at other locations in Canterbury. Interviews held at the University of Canterbury took place at the Waimairi Clinic, library or cafeteria at the Dovedale campus. For some participants, it was not always convenient to meet at the University of Canterbury, and in this case the meetings took place at other locations.

Procedure for Information Collection

The questionnaires were self-completed by participants in front of the interviewer at the first meeting. The questionnaires were formed from instruments to collect information about topics of interest to the study, such as the degree of autonomy in diabetes management,

the developmental status of the young person and self-reported exercise levels over the previous week. Some personal information was also collected at that time.

Next, participants were interviewed by the researcher using a semi-structured interview. They were asked leading and follow-up questions to assist them in describing their lived experiences more fully. The interview was recorded on a digital tape recorder and notes were made from the recording, which were then analysed qualitatively.

Information about the participant's current level of physical activity was also collected through an activity monitor, which was given to participants at the first meeting. Participants were given instructions in how to use the activity monitor and a pamphlet containing information about exercise for people with T1D (Appendix A). A second meeting time was made after the activity monitor had been worn for a week.

At the second meeting, participants returned the activity monitor to view and receive an explanation of the data. The data was uploaded onto a laptop containing the *Actilife v5.8.1* programme. Participants viewed information regarding their overall activity levels in graph form, their energy expended in chart form, and their daily activity levels in graph form. They were asked to recall activities they had performed over the week corresponding to the activity on the daily activity graphs.

At this time, participants were also asked to check a copy of the notes made at the first meeting, and a Gantt diagram made from these notes, for accuracy. After providing this information, they were thanked and given a small gift to thank them for their time. Following the second meeting, an electronic file containing the activity graphs from the activity monitor and the overall table of their physical activity over the week was emailed to all participants.

Information Sources

Information was sought from participants in three ways: Historic information was gathered from the first, semi-structured interview, while current information was collected

from a set of written questionnaires. An activity monitor collected information about exercise and physical activity levels. A second meeting was held one week after the first. During this meeting, participants checked the notes from the first interview for accuracy while accelerometer records were downloaded. The three information sources are described below.

Set of written questionnaires. A 15-minute set of questionnaires was formed beginning with personal and health-related questions and then the instruments described below. In addition to the usual demographic information gathered, the questionnaires asked about health-related information including the date of diagnosis, method of insulin administration, and any other chronic conditions experienced by the participant. Participants were asked to write the month and year that they were diagnosed with T1D. The date of diagnosis was sought to confirm that participants met the eligibility criteria of having T1D for a minimum of one year.

The method of insulin administration was also requested on the questionnaires. This information was sought because the implications of missing bolus insulin injections may be less serious for those receiving insulin continuously through a pump than for those who relied solely on multiple daily injections for insulin; this may have had an effect on participants' responses. Regarding the method of insulin administration, participants were asked to tick either a box corresponding to *Continuous pump with bolus injections* or *Multiple daily injections*.

Information regarding any other long-standing or chronic conditions was sought in order to consider whether the second condition may have had an effect on the participant's ability to manage their diabetes and to further understanding of the impact of these conditions on the participant's overall health. Participants were asked to tick either the *Yes* or *No* box for this question. The next question asked participants who had answered *Yes* to write the nature of the condition in a space provided.

Participants were informally invited to provide their height in centimetres and their weight in kilograms at the second interview. Although this information was not analysed, participants were informed that they would benefit by receiving more accurate data analysis regarding METs or “metabolic equivalents” when calculating energy expenditure via the activity monitor computer programme, *ActiLife 5.8.1*. All participants chose to provide this information. After the personal information section, the main body of the questionnaire comprised subscales from the separate questionnaires listed below.

The Daily Diabetes Management Checklist (DDMC) (Hanna & Guthrie, 2003a) – Independent Functioning Scale. This 14-item subscale was included because during adolescence, responsibility for the management of daily diabetes maintenance tasks gradually transfers from the parent or parents to the adolescent. Conflict may occur as parents and adolescents negotiate the process of transfer, and consequently some daily tasks may not be performed by either the parent or the adolescent. A measure of this transfer process was included to show the degree of behavioural autonomy of the participants, who were emerging adults, at the time of the interview. The subscale was selected for use in the study as it included a measure of behavioural autonomy in the performance of daily diabetes tasks, it was based on a validated instrument, it had demonstrated appropriate reliability, and it was able to be administered to adolescents without requiring parental involvement. The subscale has been found to have acceptable reliability and validity when used with adolescents (Hanna & Guthrie, 2003a).

The subscale asks the participant to name who performed each daily diabetes task on the day prior to the interview. For each task, participants rated themselves on four response options: the parent, the teen, both or neither. These responses signify either “adolescent totally independent” or “adolescent not totally independent”. This subscale was included on

the questionnaires under the heading *Questions about diabetes management and your parents' involvement*.

The Nondaily Diabetes Management Checklist (NDMC) (Hanna & Guthrie, 2003a) – Independent Functioning Scale. Diabetes management tasks include not only those that need to be performed daily, but also important tasks that need to be performed less frequently. The subscale was included as a measure of the transfer process to show the degree of independent functioning of emerging adults for occasional or less frequent tasks associated with managing diabetes. The subscale was selected for use in the study as it included a measure of behavioural autonomy in the performance of occasional or less frequent diabetes tasks, it was based on a validated instrument, it had demonstrated appropriate reliability, and it was able to be administered to adolescents without requiring parental involvement.

The subscale is a 20-item self-report questionnaire developed to measure independent functioning in adolescents with T1D in performing nondaily diabetes management tasks. The subscale asks the participant to name who performed each nondaily diabetes task on the day prior to the interview. For each task, participants rated themselves on four response options: the parent, the teen, both or neither. These responses signify either “adolescent totally independent” or “adolescent not totally independent”. This subscale was included on the questionnaires under the heading *Questions about diabetes management and your parents' involvement*.

Developmental Task Questionnaire (DTQ) (Seiffge-Krenke, 1998). According to the developmental model, the lifespan consists of a series of stages through which people pass from infancy to old age. Erikson (1959) developed the concept of psychosocial tasks for each stage, and highlighted the importance of identity development in adolescence. These tasks arise partly because of factors such as physical maturation, societal pressure and personal goals related to personality, and the *DTQ* is based on the developmental tasks of adolescence

initially devised by Havighurst in 1948 (as cited in Havighurst, 1972). An earlier version of the *DTQ* in German was created in 1984 by Seiffge-Krenke, Silbereisen and Otremba (as cited by Seiffge-Krenke, 1998). Seiffge-Krenke (1998) stated that the instrument has been validated; however this was not possible to verify as the German-language books containing the information were not available. Nonetheless, this unique instrument was adopted in this study because it has previously been used with typically developing adolescents (Seiffge-Krenke, 2010; Seiffge-Krenke & Gelhaar, 2008), adolescents with T1D (Seiffge-Krenke, 1998) and adolescents with other chronic conditions such as asthma (Pfeiffer & Pinquart, 2011).

The *DTQ* is a 22-item instrument that measures adolescents' self-perceived current and aspirational developmental status on 11 developmental tasks. These tasks were defined as follows: "peer group integration", "physical maturity", "separate identity", "autonomy from parents", "preparation for family life", "socio-political awareness", "occupational competence", "realistic self-perception", "individual lifestyle", "romantic relations", and "close friendship" (Seiffge-Krenke, 1998). Questions were asked in both a present form and a future form, which allowed participants to differentiate between the level of development they perceived that they had already achieved, and that which they desired for the future. The instrument therefore consisted of two subscales: achieved developmental status and desired developmental status. These subscales were included on the questionnaires under the heading *Questions about your development*.

The Summary of Diabetes Self-Care Activities (SDSCA) (Toobert et al., 2000) – Exercise Subscale (Expanded version.) This subscale comprised three items on days of exercise, daily physical activity and prescribed physical activity. Toobert et al. (2000) point out that a brief self-report instrument is often a quick and economic method of assessing diabetes self-management. Exercise and physical activity may be included in patients'

diabetes management plans as vague instructions to increase overall activity levels rather than as specific advice. This item ascertains whether or not participants have been given specific advice, providing “a set prescription against which the patient’s behaviour can be assessed” (Toobert and Glasgow, 1994, p352). Additionally, when patients’ blood glucose levels, insulin administration, diet or exercise levels are worse than expected by the healthcare provider, an instrument may be useful to determine whether this is due to miscommunication, to lack of skills, or some other reason (Toobert and Glasgow, 1994).

This subscale has previously been used with adolescents with T1D in research involving social phobia and fear of hypoglycaemia (di Battista, Hart, Greco & Glozier, 2009), dyadic illness representations and diabetes care (Gaston, Cottrell and Fullen, 2011) and self-efficacy in young adults (Johnston-Brooks, Lewis & Garg, 2002). The subscale measures “self-care” by asking for the absolute or total number of days on which exercise was performed, and also measures “adherence” by comparing this to the advice actually given by a healthcare professional (Toobert & Glasgow, 1994). The subscale has been found to have acceptable reliability and validity (Toobert et al. (2000). This subscale was included on the questionnaires under the heading *Questions about exercise*.

Adaptations to items in the questionnaire. For this study, some changes were made to the instruments used. For example, response options for the Independent Functioning subscales of the *DDMC* and *NDMC* were changed slightly in the version used in the study, with the word “teen” changed to “you” to reflect the fact that the participant may no longer be a teenager. For the achieved and desired subscales of the *DTQ*, one item on physical maturity was removed because of participants’ age as it was assumed that menarche or semenarche would have already occurred. This left a total of 20 items (ten in each subscale). Some items were also reworded slightly to sound more natural in English without changing the meaning of the task involved, or to make items gender-neutral.

Using information from the set of questionnaires. During the process of designing this study, some changes were made which affected the instruments chosen. Initially, a larger study using a younger age group (ages 18-20) was proposed and instruments were selected on this basis. As the study evolved over time, it became clear that the way instruments were used would need to change. It was decided to predominantly use information gained qualitatively, at item level, rather than quantitatively. The decision was made because of the richness of information included in each subscale and the importance of the items to this study (for example, “Who remembered to check glucose?” would tell us whether this key task of daily diabetes management was independently performed by the participant). In addition, given the uniqueness of these questionnaires, the information reported in the original studies was not directly transferable to the participants in this study. For example, the Independent Functioning subscales of the *DDMC* and *NDMC* were validated using younger adolescents ($M=14.7$, $s.d.=2.0$) from the USA (Hanna & Guthrie, 2003a) while the *DTQ* had been used with younger adolescents ($M=17.2$, $s.d.1.3$) from Germany (Seiffge-Krenke, 1998). Additionally, the validation of the achieved and desired subscales of the *DTQ* was difficult to verify and some items were changed or removed for this study. Additionally, the *SDSCA* was revised based on older adults (aged 45–67) who had predominantly T2D rather than T1D (Toobert et al., 2000). Reference to quantitative results reported in these studies is therefore used sparingly where the characteristics of the individual participant allowed close comparison or added clearly to the value of the information gathered.

Activity monitor device. The *ActiGraph GTIM Monitor* (manufactured by ActiGraph Pensacola, FL, USA) accelerometer was used because it was a physical measure of exercise and physical activity in addition to self-report measures of exercise. One such activity monitor is the *ActiGraph GTIM Monitor* (manufactured by ActiGraph Pensacola, FL, USA). The reliability and validity of the *ActiGraph GTIM Monitor* for both steps and counts

has been demonstrated in multiple studies (Rothney, Apker, Song & Chen, 2008; Sasaki, John & Freedson, 2011; Silva, Mota, Esliger & Welk, 2010). Acceptable reliability and validity has also been demonstrated when used with children and adolescents (Robusto & Trost, 2012).

The *ActiGraph GT1M Monitor* is an accelerometer that measures the number of minutes, the level of intensity and the amount of energy expended during physical activity (Actigraph, 2011a). The *ActiGraph GT1M Monitor* is biaxial, meaning it is able to measure movement on both Axis 1 (vertical plane) and Axis 2 (horizontal plane). The *ActiGraph GT1M Monitor* gathers post-filtered and accumulated information in periods of time called epochs for both axes (Actigraph, 2011a). The accumulation epoch interval used was 60 seconds and was selected for two reasons. Firstly, it was chosen because this epoch length provided the best level of detail about METs and it was considered that this information would be of interest to participants. Secondly, it meant that the activity monitor could be worn continuously for seven days without recharging the battery (Actigraph, 2011a).

The *ActiGraph GT1m Monitor* gathers activity information from Axes 1 and 2 in counts, which is a unit that increases as acceleration passes a certain threshold and is related to the intensity of physical activity (Actigraph, 2011b). The intensity of physical activity is determined by cut points for each level (Actigraph, 2011c; Freedson, Melanson & Sirard, 1998; Sasaki, John & Freedson, 1998). The cut points for the levels of expended energy were determined using an algorithm (Actigraph, 2011c). The algorithm used was the Freedson-Combination algorithm, which was based on a combination of two algorithms to obtain the most accurate results (Actigraph, 2011d; Freedson et al., 1998; Williams, 1998). The cut points are presented in Table 3.1 below.

Activity Level	Counts per minute
Sedentary	0 – 99
Light	100 – 759
Lifestyle	760 – 1951
Moderate	1952 – 5724
Vigorous	5725 – 9498
Very vigorous	9499 – ∞

Table 1. Intensity level count cut points

Gathering information using the ActiGraph GT1M Monitor. Each activity monitor was activated on a computer using the *ActiLife v.5.8.1* software programme. This process included charging the battery of the activity monitor prior to use, entering a start time for data recording to begin and selecting the epoch length. Before they were given the activity monitor, participants were instructed to wear it from the time they rose in the morning until the time they went to bed. Participants were instructed to wear the ActiGraph GT1M around the waist in order to provide the most accurate reading, to wear the activity monitor with the “Actigraph” logo facing outwards and right side up and to remove the activity monitor before showering or taking part in any activity where the activity monitor could become wet and before going to bed. Participants were informed that they would need to return the activity monitor at the second meeting so that data could be collected from the monitor.

Participants practised wearing the monitor at the initial meeting to ensure that the belt was a good fit and that they understood how to wear it. They were also given the option of taking with them an instruction sheet given to them verbally about how to wear the activity monitor (Appendix A). At this time, participants were also given a sheet containing information about exercise and T1D written for people with T1D taken from the Diabetes New Zealand website (Diabetes New Zealand website, 2012) (Appendix A). Finally, an appointment was made for the second meeting to return the activity monitor and to receive feedback after the monitor had been worn for seven consecutive days to measure their levels of physical activity.

Analysing information from the ActiGraph GTIM Monitor. The software programme used, *ActiLife v.5.8.1*, used data obtained from the activity monitor and produced Excel tables of activity levels for each day. Additionally, pdf graphs were generated by the *ActiLife v.5.8.1* programme showing the fluctuation of activity levels over the course of each day. Finally, an overall graph was generated by the *ActiLife v.5.8.1* programme which showed the amount of each level of activity (for example, sedentary) as a percentage of overall activity over the seven days data was collected. Information regarding participants' METs, or calories burnt during physical activity, was shown to participants on screen but was not analysed.

By necessity, there was some cleaning of the data. One participant, Tess, forgot to wear the activity monitor for one day. However on that day, two minutes of sedentary activity were recorded, possibly caused by Tess bumping it. The two minutes of activity were removed from further analysis. Activity recorded by the activity monitors was discussed with participants, who viewed the daily graphs and reviewed their activities over the previous seven days. Participants were emailed a copy of the graphs for their records along with a copy of the notes made at the meeting. Daily graphs were annotated with the activities that they represented.

Semi-structured interview: How Did Participants Develop Their Level of Autonomy and Physical Activity? (Appendix A) This interview aimed to ascertain changes in the type and amount of physical activity from age ten to the present age, and also aimed to ascertain the point where parents stopped taking primary responsibility for selecting activities and ensuring that participants attended them, and when participants took on this responsibility for themselves. In order to gain information about participants' experiences, a narrative interview approach was taken (Sandelowski, 1991). Narrative explanation was

chosen because it aims to describe both what happened and why it happened, therefore taking into account both actions and intentions (Sandelowski, 1991; 2000).

Because the object of recall in this case was not a single event but instead a process that took place over a period of years, a narrative-influenced semi-structured interview was used. According to Britten (1995), a semi-structured interview is organised around an initial framework of open questions, which, depending on the answers, may lead to further questions. This was the best option because multiple questions could be asked and the researcher would be able to seek further information depending on participants' responses.

Participants were asked to recall all the sports, exercise and recreational activities involving physical activity they had done, whether through school or externally, each year from age ten through to the present age. They were asked to recall the ages that they began and ended each activity, and to describe its duration and frequency and any changes over time. These questions were asked to gain an understanding of the relative importance of activities to the participant in the context of developmental changes and life events over time.

Additionally, for each activity, participants were asked for their perception of whether parents or the young person had been responsible for transport to and from each sport or activity, or whether it had been arranged through school. Participants were also asked whether transport arrangements had changed over time. These questions were asked to determine the participant's level of autonomy in taking responsibility for attending the sport or activity, and in some cases, the point where responsibility transferred from the parent to the adolescent. Prompts were pre-prepared to help participants with recall and to provide additional information about sport and activities.

Gathering information from participants using semi-structured interview.

Participants were informed that the interview was about to begin and that the microphone was about to be turned on. Participants were not given any further instructions regarding the

interview before the interviewer began asking the warm up question as described above.

Interviews were recorded with a digital voice recorder. Notes were made from the recordings, and were shared with participants at the final meeting, along with a Gantt diagram made from the notes. Participants checked the notes and diagram at the second meeting to check for accuracy, and some corrections were made at this time.

Analysing information from the semi-structured interview. The data from the interview was analysed using a qualitative descriptive approach using minimal interpretation and staying close to participants' own words. Notes made at the first interview were used to create a diagram illustrating participants' activities over time. These were presented visually in the Results section in a Gantt diagram, which illustrated activities showing the ages that participants began and ended them.

Coding of activities for anonymity. To preserve the anonymity of participants, details of the activities reported by participants were removed from reporting. Instead, activities were categorised according to the nature of the activity and its structure. Activities reported by participants were categorised into groups as follows.

1. "School Sports and Activities" (School Activities). This describes any sport or activity organised by schools. It includes the following activities: abseiling; athletics; basketball; cross-country; dance; hockey; indoor netball; kayaking; netball; Physical Education; rock climbing; rowing; rugby; soccer; softball; swimming; tennis; touch rugby; tramping; volleyball; and water polo.

2. "Club Sports and Activities" (Club Activities). This describes any coached sport or activity organised outside of schools and includes individual and team activities. It includes the following activities: athletics; dance; golf; gymnastics; horseriding; netball; Pilates; soccer; squash; swimming, table tennis; tennis; touch rugby; and trampolining.

3. “Cultural Activities including Physical Activity” (Cultural Activities). This describes when physical activity occurs during a structured activity with another primary purpose. It includes: church youth groups; Girl Guides; Kapa Haka; marching band; Scouts; and the Student Army.

4. “Planned Sports and Activities” (Planned Activities). This describes any sport or activity usually performed which may require prior planning or specialised equipment by the participant. It includes: abseiling; boating; camping; fishing; jetskiing; kayaking; kneeboarding; mountain biking; rock climbing; sailing; sea-biscuiting; and tramping.

5. “Informal Sports and Activities” (Informal Activities). This describes any sport or activity that can be performed with little prior planning by the participant. It includes: aquajogging; backyard cricket; basketball; biking; gardening; going to the gym; Pilates; running; skipping; surfing; swimming; trampolining; walking; and yoga.

6. “Non-Recreational Activity including Physical Activity” (Non-Recreational Activities). This describes any other non-recreational activity. It includes: babysitting; housework; paid work; running errands; unpaid work; volunteer work, and walking as transport.

Activities were reported under the category as described by the participant. For example, a sport performed at home with a family member rather than through school or a club was described as “Informal Sport and Exercise”. Activities were reported under both categories when participants reported taking part in the same activity through different organisations, for example, via a school team and a club team. When participants reported multiple activities from the same category, these were numbered, for example “Informal Activity 1”.

Coding of activities for autonomy. Each activity was coded as being parent-led, school based or youth-led depending on participants’ descriptions of who was responsible for

transport to and from each activity. Therefore the level of autonomy was a separate issue from the organisation managing the sport. For example, when the adolescent was transported to and from practices or games for a “School Sport or Activity” by a parent, this was coded as “parent-led” in terms of autonomy. The level of autonomy reported by participants in the semi-structured interview was indicated in the Gantt diagram by different shading for parent-led, school based or youth-led activities. If participants indicated that responsibility for transport changed, for example, if a participant gained their driver licence and began to drive to practices alone, the shading on the diagram was changed to reflect this at the age that the young person became independent.

Although mentioned by some participants, paid work and unpaid work at home was excluded from analysis because it did not represent recreational activity. The motivation for work was considered unlikely to be either intrinsic or for the purpose of maintaining health and fitness. Although not included in the analysis, information of this nature was reported in the Actigraph results section as described by participants.

Chapter 4

Results

In this chapter, each participant's responses are described individually, then a summary across all participants is described. Participants' activities and transitions are described in ascending order of age. Information about each participant was collected as described in the previous chapter.

Tess (18 years)

Historic self-rated development and diabetes care: How Tess achieved autonomy for exercise and physical activity. Tess's first activities were parent-led, as would be expected. Tess played a school sport from age 8 through to 13 years. She did this for two sessions per week, which consisted of one practice and one match, and a parent drove her to and from these sessions. Tess also took part in compulsory school-organised physical activity but found that she disliked it and stopped as soon as she was no longer required to take part at age 14. She played in another school social sport team twice a week consisting of one practice and one match per week until she was 13 years old. She travelled to matches through carpooling by parents of team members. Tess would also perform this activity informally with a close family member about once a week.

Tess began a club activity before the age of ten. A parent would typically drive her and a close family member to training sessions, which occurred three or four times a week after school, and "pretty much all Saturday" while competitions could take all weekend. This pattern of activity continued until she was 13, when she decided to quit.

"...I quit because... I really didn't like my coach, he was really, really aggressive, 'cause it gets very competitive ... and I just wasn't enjoying it anymore. It wasn't fun."

Tess enjoyed a break from competitive sports after the focus required by the activity. She began another club-based activity in her first year of high school around the age of 12 or 13. She did it with a friend, and found that:

“It was really fun, but expensive”.

Lessons were twice a week, and her transport was carpooling by a parent and her friend’s parent. Tess continued with this activity until she had just turned 14, as it was her first year of high school. She decided to quit because she had to do the activity with boys younger than herself, which made her feel awkward. When she was between 13 or 14 and 16 she began a different club activity which she chose because it was similar to her first club activity and used some of the same skills, but was more relaxed. She did this twice a week for 2 – 2.5 hours at a time. Initially she was driven there by her parents, then when she obtained her learner driver licence she drove with one of her parents, and when she obtained her restricted licence, she drove by herself. Tess decided to end the activity when she was 16 because she was feeling tired and stressed.

“...one day, with my friend, I wrote a list of all the stuff that I was doing, and I struck off, like the bottom two, because I just couldn’t, I was getting really, really stressed. And I had to strike off [the activity]. And it was a couple of months later that I was diagnosed. So that’s obviously why I was feeling so tired.”

In her final year of school, Tess played another school sport which consisted of playing two games back-to-back, which was fun for her. Overall, during this period, she was spending less time on sport as she became more involved in cultural activities. She began a second informal activity by herself when she was 16 and still took part at the time of the interview. She went about two or three times a week. It took her around 5 minutes to walk there, and she drove herself there when it rained.

Tess was asked about when she thought she began taking over her sports and activities from her parents. She said that she began transporting herself to activities when she gained her driver licence at age 16. Tess began taking holidays with her friends around that age, and parents were usually present. From age 16, she began spending holidays without parents and took part in more independent planned activities

In order to summarise the detailed information above, Tess's activities were charted in a pictorial representation according to the ages she began and finished them, and the level of autonomy she reported (see Figure 1). The figure shows the transition of responsibility for exercise as Tess grew older.

	Age											
	10	11	12	13	14	15	16	17	18			
Activities												
Club Activity 1												
School Activity 1												
School Activity 3												
School Activity 2												
Seasonal Activity 1												
Informal Activity 1												
Club Activity 2												
Club Activity 3												
Informal Activity 2												
School Activity 4												

Figure 1. Tess's growth in autonomy across activities over time. Parent-led activities are in light grey, school-based activities are in mid-grey and youth-led activities are in dark grey.

As Tess became older, her reliance on her parents decreased. In terms of autonomy, her activities were parent-led until she was 15. Her school-based activities occurred between the ages of 10 to 14. From the age of 16, Tess took over autonomy for her activities. The pattern of her activities was initially parent-led and partly school-based until the age of 16. From age 16 onward, all activities were youth-led. Tess reported involvement in a total of 10 activities, and was still involved in three of them at the time of the study.

Current self-rated development and diabetes care. On her role in daily management of diabetes using the Independent Functioning subscale of the *DDMC*, Tess perceived herself as completing most of the 14 tasks independently on the previous day. According to Tess, no one had “tested urine for ketones” or “drew up insulin injections” while both she and a parent had “prepared food when at home”. In Tess’s view, the previous day was not typical, because she went out to dinner.

Using the Independent Functioning scale of the *NDMC* to consider her role in non-daily activities involved in routine management, Tess again perceived herself as completing most of the 20 tasks independently. Tess reported both she and a parent had “noticed changes in weight” while a parent had “paid for prescriptions”, “paid for eye or dentist visit” and “paid for visit to doctor” while no one had “made regular appointments for eye exam and dentist”.

On the achieved developmental status scale of the *DTQ* Tess perceived herself as having achieved the following items: “peer group integration”, “separate identity”, “autonomy from parents”, “realistic self-perception”, “individual lifestyle” and “close friendships”. She felt she had yet to achieve the following items: “preparation for family life”, “socio-political awareness”, “occupational competence” and “romantic relationships”.

On the desired developmental status scale of the *DTQ* Tess perceived that the following items would be very important to her in the future: “autonomy from parents”, “occupational competence”, “realistic self-perception”, “individual lifestyle” and “close friendships”. She felt that “preparation for family life” and “romantic relationships” would be somewhat important, and the following items would not be important: “peer group integration”, “separate identity” and “socio-political awareness”.

On the expanded exercise scale of *SDSCA*, Tess perceived that she had participated in physical activity for at least 30 minutes on three of the seven days in the week prior to the

interview. During that week, she had also completed an exercise session on one day.

According to Tess, advice given to her was to do activity of a moderate level three times a week.

Tess' activity over one week. Tess wore the activity monitor from Monday through to Sunday, but missed out Thursday, so the daily graphs represent six days of activity rather than seven (see Figure 2.). On the week days, incidental activity from walking at approximately 8.30am was of a generally moderate level, as was walking home at about 3.00pm. On Friday afternoon, Tess was feeling ill, so she went home and went to bed. However in the evening she felt somewhat better and did some light non-recreational activity. Tess worked on Wednesday evening and on Saturday and this was at lifestyle and light levels, with some moderate activity.

“I work... so it's pretty much on your feet all the time. Walking around... fixing stuff, talking to [people], that sort of stuff. And then, at that six o'clock mark I went home, and then I [did some informal activities] with my friends... which is the vigorous, more spiky ones...”

After the informal activities on Saturday night, Tess spent most of Sunday in bed because she was still feeling unwell and wanted to get better. She reported that her activity levels on Thursday would have been similar to Tuesday. During weekdays, there was also some light and moderate activity but activity was predominantly of the lifestyle or sedentary levels.

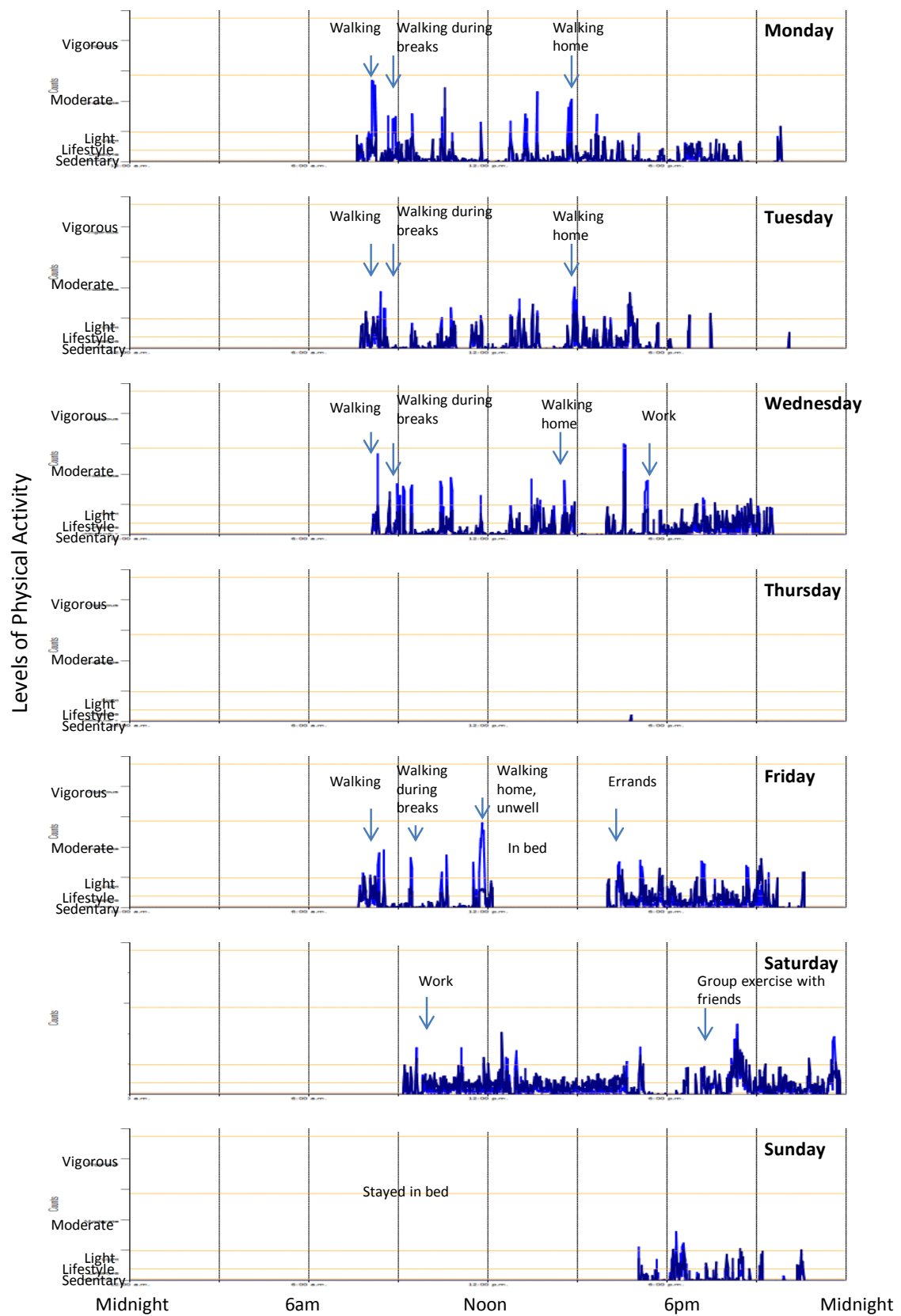


Figure 2. Tess's daily actigraphs over a week

Tess wore the activity monitor for a total of 4236 minutes (70.6 hours) over the course of the week (Appendix B), which was an average of 11.76 hours for each day she wore the monitor. Considering only the moderate and vigorous activity, Tess recorded 167 minutes over 6 days, or 27.8 minutes per day. This is around the generally recommended amount of 30 minutes per day, which is the same as the advice Tess was given by her medical team.

Elaine (age 22)

Historic self-rated development and diabetes care: How Elaine achieved autonomy for exercise and physical activity. Elaine reported that a club activity was a big part of her life. She started when she was seven, and continued at the time of the interview. A parent initially drove her to sessions once a week, then twice a week. Later, Elaine went to three sessions a week, as well as practising at home every day. She began driving herself to practices when she gained her driver licence at 16.

“And as soon as I got my restricted, that was, the day that I got it or the [activity] day, and I took myself [there] that night, Mum was like, ‘Go, I’ve got stuff to do’.”

At 16, Elaine also began teaching the activity once a week, as well as helping out the younger students during group lessons twice a week. Elaine competed nationally and sometimes internationally, which could mean up to three practices a week of up to 3 hours, in addition to daily practice at home. When she was 18, Elaine travelled overseas to compete in her sport. She had hoped to travel further and work professionally, but the global financial crisis meant that work was scarce. She was also injured and unwell, so she returned home.

“... my diabetes got a bit haywire over there as well. I picked up, possibly, it was the time of swine flu while I was there, so they suspect it was that. So I decided I was broke and I was sick so I came home... But I took a couple of months off [the activity] anyway, ‘cause I had really bad... injuries that had flared up, just from the constant practice, ‘cause it was very intense.”

Elaine was also involved with another club activity for as long as she could remember. She competed in events and was expected to practise often to keep fit. This activity was a large part of her life until she was about 15, then she quit because she was growing taller and had less time for it because she decided to focus on school and her other club activity.

From when she was 10 or 11, Elaine began informal exercise at home and her warm-up routine for her main club activity also increased her fitness. Her general fitness and sporting ability meant that she did well at school sports. Elaine represented her school at inter-school sports from the ages of about 10 to 13.

“In primary school as well, and I think in high school, I represented schools... so I did well enough to get through to the next stage.”

At around the age of 11, she began another club activity with a close family member for six months. She left because she was not enjoying it, and because its similarity to another activity of hers became confusing. When she was 15, Elaine took part in another club activity for a year to improve her performance in her main club activity, which she enjoyed. Elaine quit when there was a scheduling conflict at the age of 16.

At 16, Elaine began two new club activities, one of which she did for a year, and another which she continued to do informally up to the time of the interview. She also began another form of informal exercise at age 14 or 15. When she was 19, she joined up with a group of like-minded friends.

“[I] made a group of friends here who were, some of them were into their fitness as well... we all signed up... and we’d hit there, I think three times a week, if not more... So we’d do that, I think, Monday, Wednesday, Friday... Well, our goal was to get fit.”

Elaine enjoyed the social aspect and found that having this group of friends supported her to improve her fitness. She still did the activity at the time of the interview, but went less regularly than before because she had moved and it was less convenient to attend. Around the age of 19, Elaine began exercising informally with a training buddy in a number of ways. She mentioned that access to water sports had become more difficult since the earthquake, which had closed some local pools. More recently, she increased the number of ways she kept fit at home. In the last two years, she had begun two new activities to keep fit.

In order to summarise the detailed information above, Elaine's activities were charted in a pictorial representation according to the ages she began and finished them, and the level of autonomy she reported (see Figure 3). The figure shows the transition of responsibility for exercise as she grew older.

Elaine's activities showed a pattern of responsibility that was nearly all youth-led from an early age. Her main club activity was parent-led until she turned 16 and could drive herself, while a brief stint at another club activity was also parent-led. Elaine was involved in school-based sports from the ages of 10–14 years. Her youth-led activities began early and increased until all activities were youth-led from the age of 16. Elaine reported involvement in a total of 14 activities, and was still involved in nine of them at the time of the study.

	Age												
	10	11	12	13	14	15	16	17	18	19	20	21	22
Activities													
Club Activity 1													
Club Activity 2													
School Activity 1													
Informal Activity 1													
Club Activity 3													
Informal Activity 2													
Club Activity 4													
Club Activity 5													
Club Activity 6													
Informal Activity 3													
Informal Activity 4													
Informal Activity 5													
Informal Activity 6													
Informal Activity 7													

Figure 3. Elaine's growth in autonomy across activities over time. Parent-led activities are in light grey, school-based activities are in mid-grey and youth-led activities are in dark grey.

Current self-rated development and diabetes care. On her role in daily management of diabetes using the Independent Functioning subscale of the *DDMC*, Elaine perceived herself as completing most of the 14 tasks independently on the previous day.

According to her, no one had completed the following tasks on the previous day: “Recorded glucose in record” and “tested urine for ketones”.

Using the Independent Functioning scale of the *NDMC* to consider her role in non-daily activities involved in routine management, Elaine perceived herself as completing all 20 of the tasks independently.

On the Achieved developmental status scale of the *DTQ*, Elaine perceived herself as having achieved all but two of the developmental tasks listed. She felt she was just starting to achieve the following items: “preparation for family life” and “socio-political awareness”.

On the desired developmental status scale of the *DTQ* Elaine perceived that all items would be very important to her in the future.

On the expanded exercise scale of *SDSCA*, Elaine perceived that she had participated in physical activity for at least 30 minutes on six of the seven days in the week prior to the interview. During that week, she had also completed an exercise session on four days. According to Elaine, advice given to her was to continue with her current exercise schedule, which included daily practice of her club activity.

Elaine’s activity over one week. She wore the activity monitor from Friday through to Thursday (see Figure 4.). On Sunday and Monday, Elaine worked and her activity levels were generally light. She practised her club activity on five of the seven days recorded, and at these times her activity levels were mainly at vigorous and very vigorous levels, with some activity at the moderate level. On Saturday afternoon Elaine spent some time doing informal activities, which put her activity levels into the vigorous range while on Monday evening, other informal activities led to very vigorous activity. Non-recreational activity on Tuesday afternoon led to moderate and vigorous levels, while Elaine’s other non-recreational activity on Wednesday afternoon was mainly of lifestyle and light activity levels.

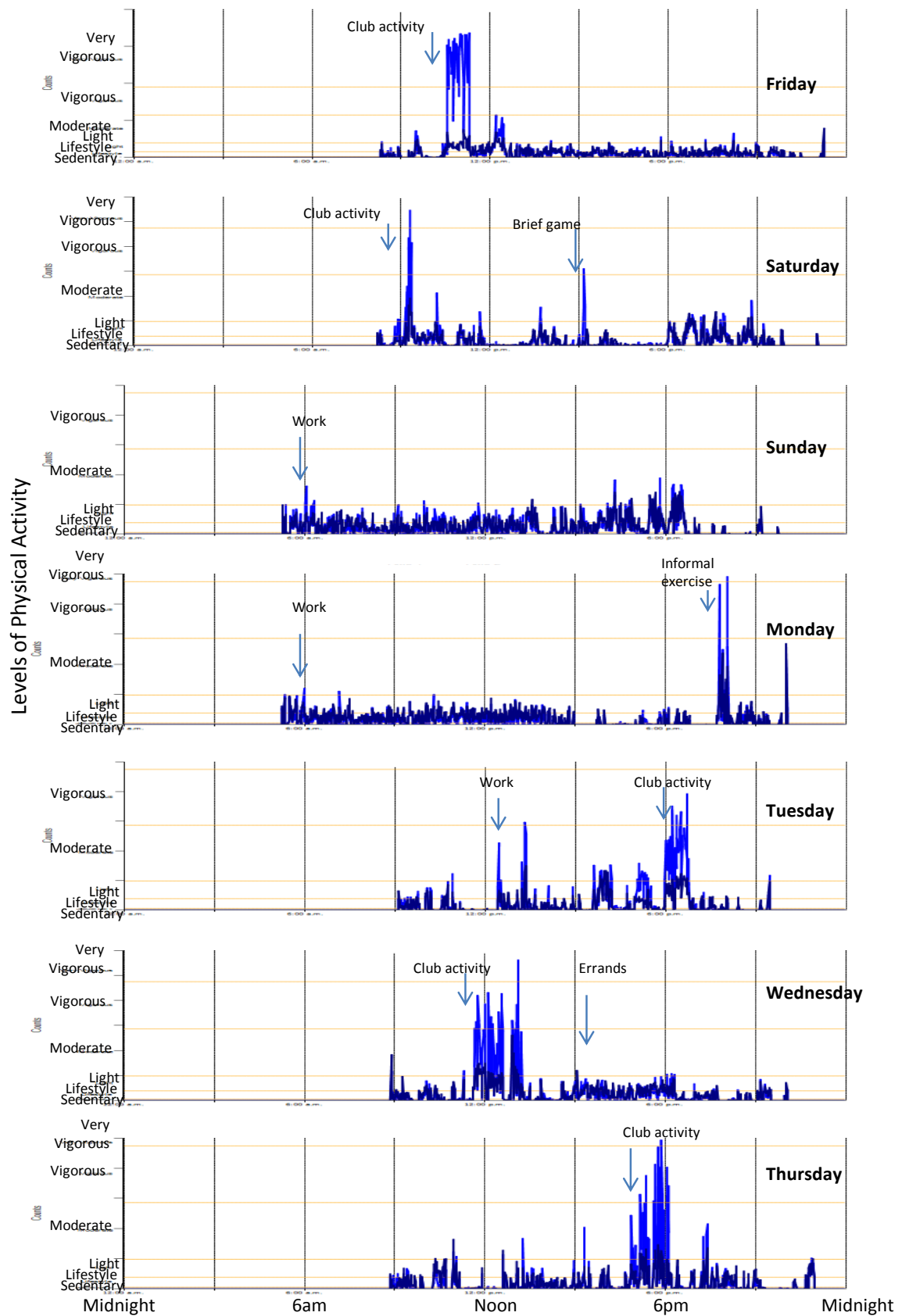


Figure 4. Elaine's daily actigraphs over a week

Elaine wore the activity monitor for a total of 5989 minutes (99.82 hours) over the course of the week, which was an average of 14.26 hours for each day she wore the monitor (see Appendix B.). Considering only the moderate, vigorous and very vigorous activity, Elaine recorded 345 minutes over the week, or 49.29 minutes per day. These activities were mainly her club activity and informal activities. This is above the generally recommended amount of 30 minutes per day, and is consistent with the advice she was given by her medical team.

Raewyn (24 years)

How Raewyn developed to this level of autonomy and physical activity. Raewyn's first activities were parent-led. Raewyn took part in cultural activities, which she enjoyed from age 9 until 14. Either a parent would drop her off or would walk her there. While she was growing up, Raewyn's family would go on planned activities in the holidays. She described day-long trips which involved hours of hard walking.

“On foot, like we'd take the road in as far as we could go but a lot of it was bush bashing, like through swamp, through thick trees, like there would be no path, and we'd just be going by [their] nose and just following [their] feet and hoping that we wouldn't get lost along the way.”

Raewyn family would go on various trips to do these activities. She also described going on family activities in the weekends, mostly when she was between ages 8 and 10, which could take up to three or four hours. These activities finished when she was 12 and there was a change in her family situation.

Raewyn described doing a lot of walking with a close family member when she was younger. When she turned 13, she began to go for walks by herself when she was bored or for pleasure. Raewyn was also involved in another cultural activity from when she was in primary school until she finished intermediate school aged 12. The practices were about once a week unless a performance was scheduled, when practices were held twice a week. Performances could be long, and she described them as taking up to half a day.

Raewyn started a club activity when she was 6 and continued until she was 16. Practices were once a week until she turned 13, then they were twice a week with extra practice at home.

“I'd probably be practising all the time at home. Yeah, just whenever I was bored, I used to have to close off all the doors to the lounge, kick everybody out of the room to

practise, like for hours... I was still [practising] in my room, probably the most activity that I got... like you couldn't stop me! Yeah it was a huge part of my life."

Raewyn enjoyed the structure of these lessons, the way that her instructor pushed her to do her best, and working towards a performance at the end of the year. She used to walk to her sessions with a parent until the location changed when she was 11, then they would travel by bus. Just before she turned 16, Raewyn moved to another city and began weekly sessions with a new instructor.

"It was once a week but the classes were pretty basic, classes, and yeah they just weren't pushing me as much as I liked 'cause I was used to very, um, very structured, very pushed... hard line, almost military-style... and you know you'd go there, and you wouldn't even learn something new, you'd just sort of play around".

Raewyn did not enjoy the change in structure of sessions, which no longer focused on her preferred activity and now included a range of activities. She decided to quit at the end of the year.

Moving to another city led to some changes in the pattern of Raewyn's activities. She took the bus to school, but her new home was at the top of a hill and the bus stop was at the bottom. As well as a 20-minute uphill walk every day after school, she would also walk in the hills and go for longer walks about twice a week. Raewyn and a family member continued with planned activities for the first year after she moved.

When Raewyn was 17, she became involved with activities through school. She loved it because it involved a mixture of theory and practical activities. The course included practices one night a week for half the year, and four week-long trips per year. She became involved with planned activities with friends, which became a big part of her life. When she was 22, she became unwell and it was several months before she was correctly diagnosed. It was a difficult time, and she stopped her study and activities to focus on getting better.

“And then I got diagnosed with Type 1 diabetes halfway through, and so I didn’t finish.... And then I took a year off physical activity... ‘cause I was very sick.”

Raewyn expressed some frustration about the difficulty of managing her diabetes. For the rest of that year and the following year, she experimented with the amounts of physical activity and insulin she needed as she regained her health and fitness. At first, this was difficult because her body was still producing some insulin. When she no longer produced any of her own insulin, it was easier to calculate the amount required. Raewyn returned to study and exercise when she was 24. She found that with experience, she was learning about how different types of exercise would affect her insulin metabolism, and she was better able to predict issues such as delayed hypoglycaemia. She also began another informal activity that year, and went walking in the hills three times a week with a friend.

In order to summarise the detailed information above, Raewyn’s activities were charted in a pictorial representation according to the ages she began and finished them, and the level of autonomy she reported (see Figure 5). The figure shows the transition of responsibility for exercise as Raewyn grew older.

	Age														
	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Activities															
Informal Activity 1															
Informal Activity 2															
Club Activity 1															
Cultural Activity 1															
Cultural Activity 2															
Seasonal Activity 1															
Seasonal Activity 2															
Seasonal Activity 3															
Seasonal Activity 4															
Seasonal Activity 5															
Seasonal Activity 6															
Informal Activity 3															

Figure 5. Raewyn’s growth in autonomy across activities over time. Parent-led activities are in light grey, school-based activities are in mid-grey and youth-led activities are in dark grey.

As Raewyn became older, her reliance on her parents decreased. Her activities were originally parent-led with a school-based activity until age 12. Raewyn took a year off physical activity when she was 23 due to her health, and resumed her activities and began another activity at age 24. The pattern of Raewyn's activities was mainly parent-based until the age of 16. At age 17, most activities were school based, with one youth-led activity. From age 18 onward, all activities were youth-led. Raewyn reported involvement in a total of 12 activities, and was still involved in six of them at the time of the study.

Self-rated development and diabetes care. On her role in daily management of diabetes using the Independent Functioning subscale of the *DDMC*, Raewyn perceived herself as completing about two thirds of the 14 tasks independently on the previous day. According to Raewyn, no one had completed the following tasks on the previous day: “Remembered to check glucose”, “checked glucose”, “recorded glucose in record”, “tested urine for ketones” and “calculated insulin dose”.

Using the Independent Functioning scale of the *NDMC* to consider her role in non-daily activities involved in routine management, Raewyn perceived herself as completing all of the 20 tasks independently.

On the achieved developmental status scale of the *DTQ* Raewyn perceived herself as having achieved the following items: “peer group integration”, “separate identity”, “autonomy from parents”, “socio-political awareness”, “realistic self-perception”, “individual lifestyle”, “romantic relationships” and “close friendships”. She felt she was just starting to achieve “occupational competence” and “realistic self-perception” and had yet to achieve “preparation for family life”.

On the desired developmental status scale of the *DTQ* Raewyn perceived that all items would be very important to her in the future.

On the expanded exercise scale of *SDSCA*, Raewyn perceived that she had participated in physical activity for at least 30 minutes on three of the seven days in the week prior to the interview. During that week, she had also completed an exercise session on three days. According to Raewyn, she had not been given any advice about exercise by her healthcare team.

Raewyn's activity over one week. Raewyn wore the activity monitor from Tuesday through to Monday, although she forgot to wear the monitor on Sunday, which means that this data represents six days instead of seven (see Figure 6.). During non-recreational activity, levels were generally light and lifestyle, with some occasional activity at the moderate level. Raewyn also reported a general burst of activity before leaving for work.

“...I was racing around to ... get everything organised, and ironed and out the door, and the gap was probably when I was driving, and working a shift.”

Raewyn did other non-recreational activity on four days of the week, which mainly ranged between lifestyle and moderate levels. She reported that on Sunday, when she forgot the activity monitor, her day was similar to Friday.

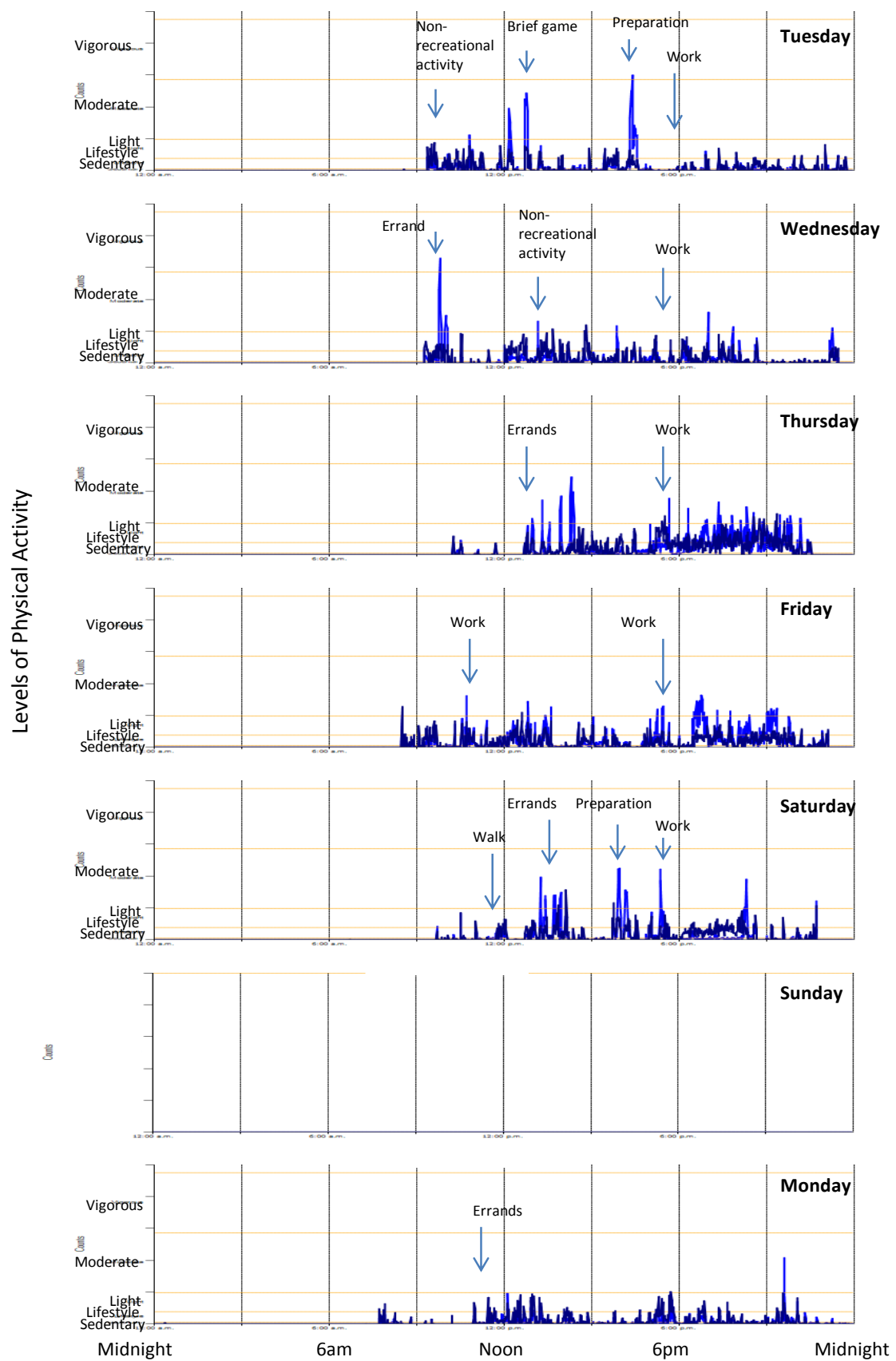


Figure 6. Raewyn's daily actigraphs over a week

Raewyn wore the activity monitor for a total of 4900 minutes (81.7 hours) over six days during the week, which was an average of 13.6 hours for each day she wore the monitor (see Appendix B). Considering only the moderate and vigorous activity, Raewyn recorded 135 minutes over the six days, or 22.5 minutes per day. These activities were non-recreational activities. This is less than the generally recommended amount of 30 minutes per day.

Lucy (24 years)

Historic self-rated development and diabetes care: How Lucy achieved autonomy for exercise and physical activity. Lucy's first activities were parent-led, as would be expected. She described a very active childhood, with a different activity every night of the week. Her main activity was a club sport, which she began when she was 18 months old and continued until she was 23. Lucy competed until the age of 16 and had practices on weeknights and Saturday mornings, which were usually around 1.5 hours. Her parents drove her to practices and competitions, which took up a weekend when they occurred. When she was 16, Lucy stopped competing due to the time commitment.

"I just got sick of the, the amount of training, it just took your life up."

Lucy continued the activity recreationally because she enjoyed it. She finally stopped when she was 23 and the earthquakes led to the closure of facilities in the area. She did another club activity from age 5 through to age 16. She had a two-hour session once per week, and her parents took her to practices. Lucy quit when she was 16 because the tight-fitting uniform began to make her feel uncomfortable and parts of the uniform hurt.

"Getting into [them] was just horrible. And... I just, it wasn't bad but, maybe got a little bit more self-conscious... getting to sixth form you kind of care about that stuff?"

Although she quit the activity, Lucy and a friend took up a similar one when she was 19. She described this as being something she had always wanted to do. She was responsible for getting herself to these practices.

Lucy attended a cultural activity once a week from the ages of 10 to 13, and her parents took her there. She did planned activities with her family from age 10 until she was about 16. Her family members were keen to go together, and the whole family would go on

short trips on some weekends and some longer trips during school holidays. She initially enjoyed the trips, but grew less interested in them and finally stopped going when she was 16.

Lucy was involved in individual school sports until she left school aged 18. She also played a team sport in summer for a school team from when she was 11 to when she was 13, and finished when she began high school. She played another club team sport every winter, beginning at primary school and continuing until the time of the interview. Lucy took a year off this sport in her final year of school when she was 18 because she wanted some free time in her weekends, then re-joined a club when she began attending university. Her parents drove her to practices until she gained her driver licence when she was 18.

When she was 15, Lucy became involved in several new sports through her school. She did one activity until she was 18 and she finished school. Games were once a week and there was also one weekly practice. When she was 15, she also began playing a social team sport, which she did for two seasons and quit when she was 17. Lucy also began a winter team sport for school when she was 15 until she was 18. She described playing it as intense, with twice-weekly practices, full-length games and school competitions that meant the team had to travel. She found the sport to be fun and enjoyed the social aspect, but decided to stop playing because of the injuries it caused.

“I can’t believe I used to play! It was fun, ‘cause I mean it’s a good pick up line, I guess when you say ‘Hey look, I play [sport]’... [I quit because] I didn’t want to get hurt at all, or break any more bones! I had broken fingers, concussions, I had secondary concussion, like it was just... too intense. It *is* a man’s sport, I hate to say it, but it is.”

Lucy started meeting up with her friends to go for a walk or do other informal activities from the age of 16. She saw this as an opportunity to get out of the house and talk to her friends in private. She was still doing these activities at the time of the interview, and

planned to resume daily walks. Lucy began another team game from the age of 17 as a summer sport through her club, and she continued to play socially up until the time of the interview.

When she was 18, Lucy began other informal activities to increase her fitness. She would sometimes go running with a training buddy. Between ages 18 and 22, Lucy was able to access facilities where she could easily do informal sports and activities. She stopped going when she was 22 and access became more difficult. At the time of the interview, Lucy had recently begun another informal activity.

In order to summarise the detailed information above, Lucy's activities were charted in a pictorial representation according to the ages she began and finished them, and the level of autonomy she reported (see Figure 7). The figure shows the transition of responsibility for exercise as Lucy grew older.

	Age														
	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Activities															
Club Activity 1															
Club Activity 2															
Club Activity 3															
School Activity 1															
Seasonal Activity 1															
Cultural Activity															
Seasonal Activity 2															
School Activity 2															
School Activity 3															
School Activity 4															
School Activity 5															
Club Activity 4															
Informal Activity 1															
Informal Activity 2															
Informal Activity 3															
Club Activity 5															
Informal Activity 4															

Figure 7. Lucy's growth in autonomy over time. Parent-led activities are in light grey, school-based activities are in mid-grey and youth-led activities are in dark grey.

As Lucy grew older, her reliance on her parents decreased. Some activities were initially parent-led, but Lucy took over responsibility from the age of 16 for two of them and after the age of 18 for one sport. The pattern of Lucy's activities was mainly parent-led until the age of 17, with one school based activity. Age 16 introduced several adolescent-led activities, while age 17 was part parent-led and part youth-led. Age 18 was mainly youth-led, and all activities were youth-led from the age of 19 onward. Lucy reported involvement in a total of 17 activities, and was still involved in six of them at the time of the study.

Self-rated development and diabetes care. On her role in daily management of diabetes using the Independent Functioning subscale of the *DDMC*, Lucy perceived herself as completing most of the 14 tasks independently on the previous day. According to Lucy, no one had "recorded glucose in record" or "tested urine for ketones".

Using the Independent Functioning scale of the *NDMC* to consider her role in non-daily activities involved in routine management, Lucy again perceived herself as completing most of the 20 tasks independently. Lucy reported that a parent had "paid for visit to the doctor", while no one had "called the doctor or nurse for help or advice".

On the achieved developmental status scale of the *DTQ* Lucy perceived herself as having achieved the following items: "peer group integration", "socio-political awareness", "realistic self-perception", "individual lifestyle", "romantic relationships" and "close friendships". She felt she was just starting to achieve "separate identity", "autonomy from parents" and "occupational competence" and had yet to achieve "preparation for family life".

On the desired developmental status scale of the *DTQ* Lucy perceived that all items would be very important to her in the future.

On the expanded exercise scale of *SDSCA*, Lucy perceived that she had participated in physical activity for at least 30 minutes on five of the seven days in the week prior to the

interview. During that week, she had also completed an exercise session on three days.

According to Lucy, she had not been given any advice about exercise by her healthcare team.

Lucy's activity over one week. Lucy wore the activity monitor during waking hours from Wednesday through to Tuesday, although she forgot to wear the monitor on Saturday morning, so the activity monitor did not gather data during that period (see Figure 8.).

On week days, incidental activity involved walking to work around 8am, which was moderate activity. During working hours, Lucy's activity varied between sedentary, lifestyle and light levels except on Thursday, when her activity was less sedentary and included some activity in the moderate range. On Thursday, Friday and Monday, Lucy took a walk which was moderate activity. Non-recreational activity on Saturday, Sunday and Monday led to activity levels between lifestyle and moderate levels. On Tuesday night, Lucy did more non-recreational activity and levels ranged between lifestyle to moderate. On Monday evening, Lucy decided to go for a walk, which was moderate activity.

“I went for a walk for an hour, ‘cause I hadn’t done anything over the weekend, so I was like, I need to go do something.”

On Wednesday evening, Lucy played sport, and this was moderate activity. There were some spikes in her activity before going to bed on some nights.

“If I’m feeling lazy I’ll do some jumps or something, you know like in the privacy of my own bedroom, just to make me feel like I’ve done something? So that possibly could be it. Just doing like, I don’t know, start jumping up and down? ... Otherwise at the end of the day I feel like, oh, I’ve just been sitting down...”

Lucy was unable to remember exactly what she had done, but she thought that she may have done some extra exercise on the days she had been less physically active than usual. On Saturday night, Lucy took part in informal activities until the early hours of Sunday morning, with levels from sedentary to moderate.

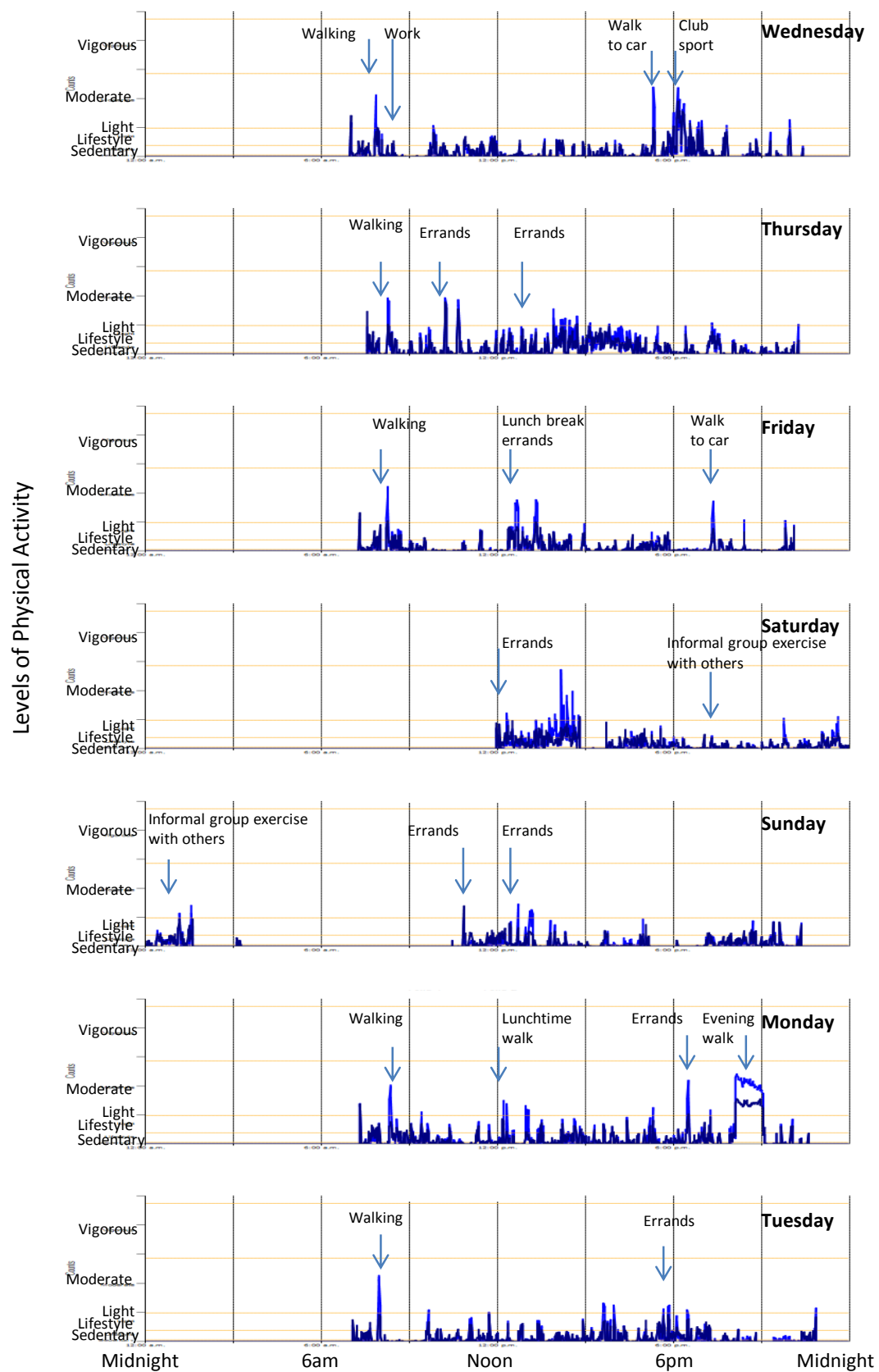


Figure 8. Lucy's daily actigraphs over a week

Lucy wore the activity monitor for a total of 5938 minutes (98.9 hours) over the course of the week, which was an average of 14.1 hours for each day she wore it (see Appendix B.). Considering only the moderate activity, she recorded 195 minutes over the week, or 27.9 minutes per day. These activities were mainly informal activity, non-recreational activity and club sports. This is around the generally recommended amount of 30 minutes per day.

Kelly (24 years)

Historic self-rated development and diabetes care: How Kelly achieved autonomy for exercise and physical activity. Kelly's first activities were parent-led, as would be expected. She took part in cultural activities between the ages of 8 and 12. Practices were two or three times a week and usually lasted an hour but occasionally lasted 2 or 2.5 hours.

Kelly played a school sport from ages 8 to 12. She played for school teams during this time, and when she was 12 she also played in a team representing her area. She was driven to practices by a parent. Kelly quit at the end of intermediate school when she was 12, partly because she felt it was unfeminine.

"I didn't really enjoy it... And I enjoyed [another sport] more than I did [this sport], so yeah, I think that was just why I gave up. And none of my girlfriends really played [it] either, so yeah, it was a real boy's sport, and because it was mixed, 'cause I'm a real girl, so... [laughs]. Yeah I didn't really like it that much, I think I was just trying to do it 'cause [close family member] wanted me to."

She and her family used to exercise together. They did this from when Kelly was young until she was 13 and decided to stop. She said that this usually took between an hour to an hour and a half, and usually involved a picnic in the park or at the sea. These happened on most Sundays. Kelly's friends would also come along with the family if they had stayed at her place the night before. From as early as she could remember, Kelly and her family did a variety of planned activities every summer holiday. At the time of the study, Kelly still did these activities with her family, and they would often go together with their extended family.

Kelly began playing another school sport when she was 10 and continued playing until she was 15. She played for a school team until the age of 12, when she finished intermediate school, then played for a social team for the first three years of high school until

she was 15. A close family member became involved with the team and took her to practices. Kelly's friends were in the social team, which she described as playing hard during the weekly game but not during the weekly practice. She decided to quit the sport because she wanted more time for her social life.

There was a relative lack of activities when she was 16, apart from organised school sports. From when she began school until she left school at 17, she took part in organised school sports. Kelly mentioned that her school sports led to her diagnosis when she was 12, when the school principal saw her and recognised that she was too thin. This led to Kelly's diagnosis of T1D and she began to receive treatment.

When Kelly left school at age 17, she immediately started an informal activity so that she could exercise regularly because her new job was sedentary. She drove herself there and back. However, she found that she did not go as often as she had hoped, and went there about once per fortnight for a year between the ages of 17 and 18. Kelly quit after a year because she rarely exercised.

“Like it was, it was like when you first sign up and you go all the time? And then you just don't go, it was like that... So I was just paying for it and not going, yup.”

After finishing there, Kelly said she did not do much in the way of exercise apart from the summer activities with close family members. When she was 22, Kelly and a close family member began going for long walks together in the hills. They took five-kilometre walks about four or five times a week because Kelly wanted to improve her fitness.

“...because I just wanted to be healthier, so I didn't need or want to lose weight, I just wanted to be healthier. But because I was walking, I was losing weight, and toning up and that sort of thing as well.”

Kelly went for walks for a year and a half, and stopped when she took up part time work. At the time of the interview, Kelly also went for walks with family during weekends, as they had one “family day” a week set aside for doing activities together. These activities also included group activities involving exercise. Kelly said that the family had recently taken up their summer activities again, and this usually meant a day trip on fine weekends.

In order to summarise the detailed information above, Kelly’s activities were charted in a pictorial representation according to the ages she began and finished them, and the level of autonomy she reported (see Figure 9). The figure shows the transition of responsibility for exercise as Kelly grew older.

	Age														
	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Activities															
School Activity 1															
School Activity 2															
School Activity 3															
Informal Activity 1															
Cultural Activity															
Seasonal Activity															
Informal Activity 2															
Informal Activity 3															

Figure 9. Kelly’s growth in autonomy across activities over time. Parent-led activities are in light grey, school-based activities are in mid-grey and youth-led activities are in dark grey.

Kelly’s parent-led activities team sports, cultural activities, planned activities and informal activities while school-base activities included school sports. Activities that were youth-led included individual exercise and planned activities from the age of 21. There was a relative lack of activities at ages 19 and 21. The pattern of Kelly’s activities was initially parent-led with one school based activity until the age of 17, when it was equal parts parent-led, school-based and youth-led. At age 18, Kelly’s activities were half parent-led and half youth-led, however from ages 19-20 Kelly’s activity reverted to parent-led. All activities were youth-led from the age of 21. Kelly reported involvement in a total of 8 activities, and was still involved in two of them at the time of the study.

Self-rated development and diabetes care. On her role in daily management of diabetes using the Independent Functioning subscale of the *DDMC*, Kelly rated herself as completing about three quarters of the tasks independently on the previous day. According to Kelly, no one had “recorded glucose in record”, “tested urine for ketones”, “calculated insulin dose” or “made sure exercised”.

Using the Independent Functioning scale of the *NDMC* to consider her role in non-daily activities involved in routine management, Kelly perceived herself as completing most of the 20 tasks independently. Kelly reported that no one had “paid for visit to the doctor”, “called the doctor or nurse for help or advice” or “told adults (teachers, relatives) about having diabetes”.

On the achieved developmental status scale of the *DTQ*, Kelly perceived herself as having achieved the following items: “peer group integration”, “separate identity”, “autonomy from parents”, “preparation for family life”, “realistic self-perception”, “individual lifestyle”, “romantic relationships” and “close friendships”. She felt she was just starting to achieve “socio-political awareness”, and had yet to achieve “occupational competence”.

On the desired developmental status scale of the *DTQ* Kelly perceived that all items would be very important to her in the future apart from “socio-political awareness”, which she felt would be somewhat important to her in the future.

On the expanded exercise scale of *SDSCA*, Kelly perceived that she had participated in physical activity for at least 30 minutes on one of the seven days in the week prior to the interview. During that week, she had also completed an exercise session on one day. According to Kelly, the exercise advice she was given by her healthcare team included getting low level exercise (such as walking) every day, and exercise continuously for at least 20 minutes at least 3 times a week.

Kelly's activity over one week. Kelly wore the activity monitor for seven days from Thursday through to Wednesday (see Figure 10.). However on Thursday, Sunday and Tuesday mornings, there are gaps of 1 to 1.5 hours where Kelly took off the activity monitor and forgot to put it back on, therefore the activity monitor did not gather data during those periods. Kelly worked three days per week and during those periods her activity levels were lifestyle and light. On Thursday, Monday and Tuesday she ran errands which led to moderate spikes of activity as they involved walking uphill.

During weekdays, Kelly described a pattern where she got up around seven and engaged in household chores and errands during the day. She worked on three days. On Saturday, she spent five to six hours driving to and from another city, which was mainly sedentary to light activity.

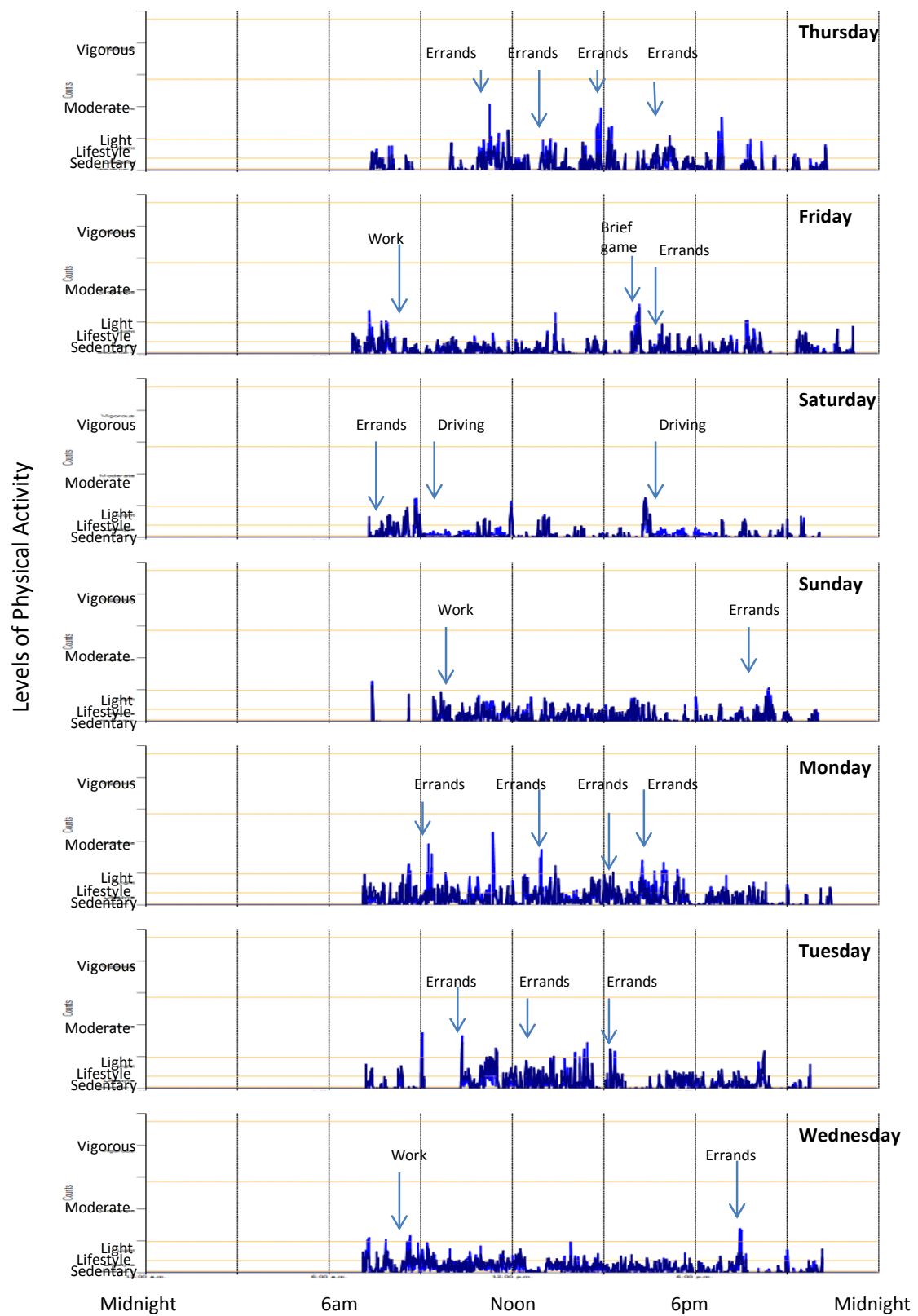


Figure 10. Kelly's daily actigraphs over a week

Kelly wore the activity monitor for a total of 6100 minutes (101.7 hours) over the course of the week, which was an average of 14.5 hours for each day she wore the monitor (see Appendix B). Considering only the moderate activity, She recorded 73 minutes over the week, or 10.4 minutes per day. These activities were mainly errands and other non-recreational activity. She also recorded 462 minutes of light activity over the week, or 66 minutes per day. Kelly's moderate activity levels are less than the generally recommended amount of 30 minutes of moderate activity per day, but her overall activity is consistent with the advice she was given to about her exercise from her medical team and may have been consistent with her health condition.

Summary of participants

In this section, participants' data will be summarised and considered across the group.

Historic self-rated development and diabetes care: Development of autonomy for activities across participants. Participants showed differing patterns in levels of autonomy for their activities throughout adolescence. Tess's overall pattern of autonomy is one that was mainly parent-led with some school-based activities before all activities became youth-led at the age of 16. Elaine's overall pattern of autonomy is one that was nearly all youth-led from childhood, with some school based activities and parent-led activities which stopped when Elaine was 16. Raewyn's overall pattern was of mainly parent-led activities, then youth-led, then mainly school-based for a year, before all activities became youth-led at the age of 18. Lucy's overall pattern began with parent-led activities, gradually became mainly school based but with some parent-led activities, through to school based with some youth-led activities, until all activities were youth-led from 19. Kelly's overall pattern was mainly parent-led, to equal parts parent, school and youth-led, to youth-led, to a break in activities then back to youth-led. A summary of participants' activities were charted according to the ages they began and finished them, and the level of autonomy reported (see Figure 11).

	Age														
Participant	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Tess															
Elaine															
Raewyn															
Lucy															
Kelly															

Figure 11. Growth in autonomy for activities across participants. Lower autonomy is in light grey, medium autonomy is in mid-grey and higher autonomy is in dark grey.

Participants each reported a range of total activities performed from age ten through to the time of interview. Tess reported a total of 10 activities, including three that she continued to perform at the present time. Elaine reported a total of 14 activities, including nine that she continued to perform at the present time. Raewyn reported a total of 12

activities, including six that she continued to perform at the present time. Lucy reported a total of 17 activities, including six that she continued to perform at the present time. Kelly reported a total of eight activities, including two that she continued to perform at the present time.

Current self-rated development and diabetes care across participants.

Participants rated themselves on the Independent Functioning subscale of the *DDMC*. There were 14 items relating to responsibility for daily diabetes management tasks, and the group completed nearly all tasks with little variation among them. Elaine and Lucy completed the most items, then Tess, then Kelly, while Raewyn completed the fewest.

Participants rated themselves Independent Functioning subscale of the *NDMC*. There were twenty items relating to responsibility for daily diabetes management tasks, and the group completed nearly all of them with little variation among them. Raewyn and Elaine completed the most items, then Lucy, then Kelly, while Tess completed the fewest.

Participants' rated themselves on the achieved developmental status subscale of the *DTQ*. There were 10 items relating to developmental status. There was a split in self-ratings among participants, with Elaine, Kelly Raewyn and Lucy rating themselves quite highly, while Tess rated herself as lower than the others. Elaine rated herself the highest, then Kelly, then Raewyn, then Lucy, then Tess.

Participants' rated themselves on the desired developmental status subscale of the *DTQ*. As with the achieved scale, responses to the desired scale showed a split in self-ratings with Elaine, Kelly Raewyn and Lucy rating themselves quite highly, while Tess rated herself as lower than the others. Elaine, Raewyn and Lucy rated themselves at the maximum, closely followed by Kelly, then followed by Tess.

Self-reported days in the previous week when participants completed physical activity are as follows: Elaine reported the most at six days, then Lucy at five days, then Tess and

Raewyn at three days, followed by Kelly at one day. Self-reported days in the previous week when participants completed an exercise session are as follows: Elaine reported the most at four days, then Raewyn and Lucy at three days, then Tess and Kelly at one day. There was considerable variation in advice given to participants about exercise. Tess was told to do moderate exercise three times a week; Elaine was told to continue with her usual exercise schedule; Kelly was told to get low level exercise (such as walking) every day and to exercise continuously for at least 20 minutes at least 3 times a week, and; Raewyn and Lucy reported that they had been given no advice about exercise.

Current levels of physical activity across the group. Participants' activity levels across the week are illustrated below as a group (see Figure 12.). Participants varied considerably in their levels of physical activity over the course of the week, which reflects the maximum activity level for each participant and is evident in the maximum count number on each scale. For Tess, most activity occurred when walking to or from activities, through other non-recreational activity and through informal activity. For Elaine, most activity occurred when practising her club activity. For Raewyn, most activity occurred when she was working or doing other non-recreational activity. For Lucy, activity occurred when she was walking to or from activities, doing non-recreational activity, doing informal activity or doing club sport. For Kelly, most activity occurred when doing non-recreational activity.

Over the course of the week, participants wore the activity monitor for differing amounts of time. Participants were busy, and two forgot to wear the monitor for a day, while other participants forgot to wear the monitor for shorter periods of time. Because of this, percentages of the intensity of activity levels for the week are also presented across participants (Appendix B)

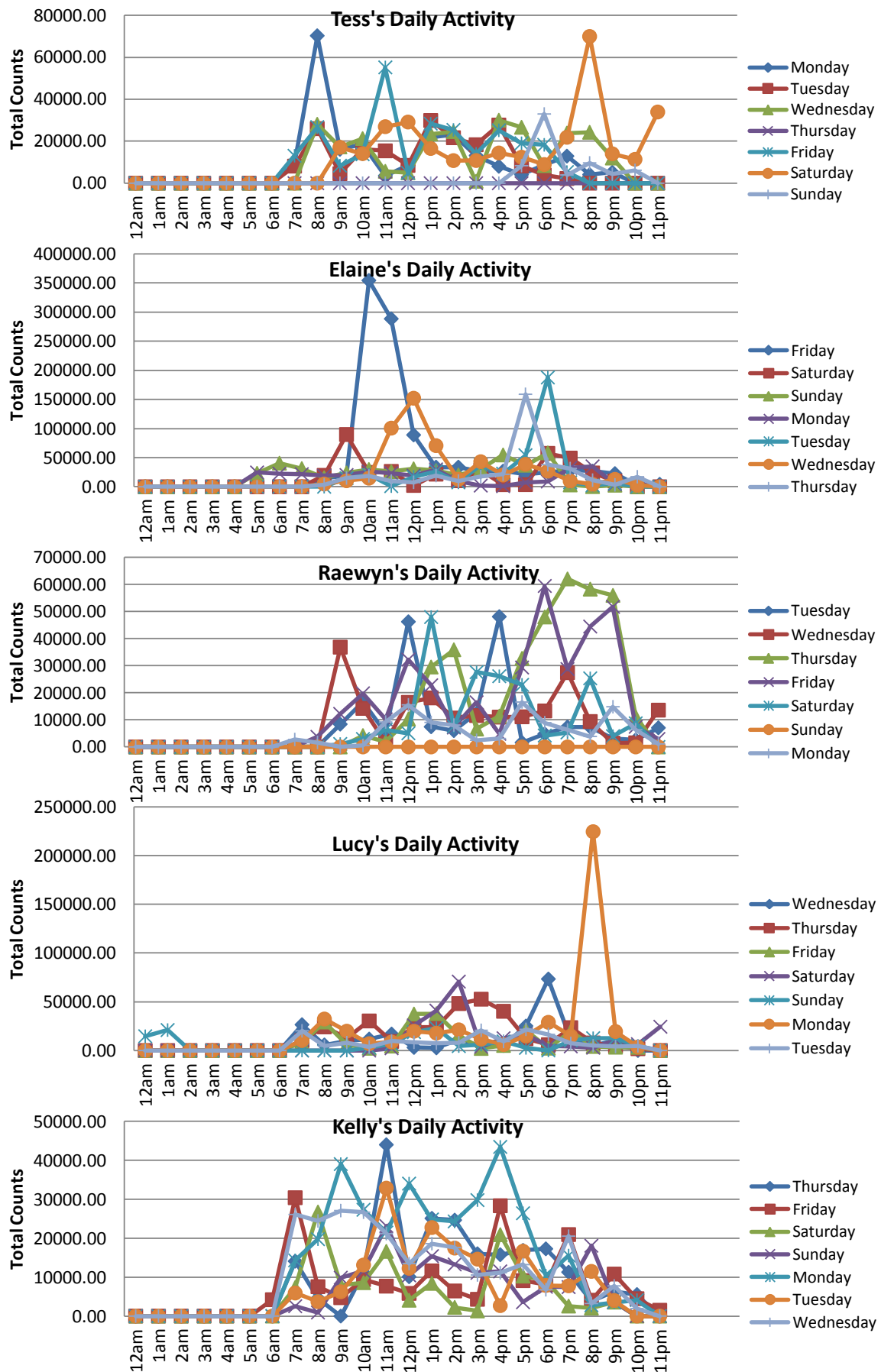


Figure 12. Participants daily activity level counts over the course of a week

Of the participants, Elaine's activity was the highest for all levels apart from sedentary activity. Only Elaine recorded levels of very vigorous activity and more than a few minutes of vigorous activity over the week, and there was a large difference between her activity levels and those of the other participants. Tess had the next most moderate and vigorous activity levels and relatively more of the lower activity levels such as light, lifestyle and sedentary levels. Lucy had the next most moderate activity levels, however she did not record any vigorous activity over the week. Raewyn had some vigorous activity and relatively low sedentary levels, but relatively less moderate activity. Kelly had the second lowest level of sedentary activity, however she recorded lower levels of moderate activity and did not record any vigorous activity.

Chapter 5

Discussion

This study has taken a novel and interesting approach to exploring a complex topic, namely perceptions of autonomy development for exercise in emerging adults with T1D during adolescence, and current functioning in terms of diabetes self-management and exercise. This study used a qualitative descriptive approach that has allowed an in-depth exploration of the topic. It has established the emergence of participants' autonomy development for exercise through a semi-structured interview. It has gathered and analysed information about their current functioning from self-report questionnaires. The study has also established participants' current pattern of exercise, using an activity monitor, as well as ascertaining whether their activity levels have achieved the current guidelines for physical activity for people with T1D.

There were five participants who took part in the study, all young women. Four of the participants were aged between 22 and 24 years, except for Tess, the youngest, who was 18 years old. Tess was diagnosed two years earlier at age 16 and Raewyn (aged 24) was also diagnosed only two years earlier, whereas the others had had a longer period to adjust to their condition. For example, Elaine (aged 22) was diagnosed at age 15, Kelly (aged 24) was diagnosed at age 12 and Lucy (aged 24) was diagnosed at age two. The research question was partially answered by this study, and the key findings are summarised below.

Findings of the Research

Tess. Tess described a successful transition from parent-led to adolescent-led exercise and took full responsibility for managing her exercise. Tess has transitioned from mainly parent-led and partly school-based activities in childhood, to all youth-led activities from the age of 16 onwards. She attributed this to gaining her driver licence at this age. For Tess, her health may have been perceived as a barrier to exercise and at age 16 she reduced her

exercise activities. It may be that she prioritised academic and cultural activities. Tess self-identified strengths and weaknesses in her diabetes self-management and her current developmental status.

It was difficult to see many patterns in the data due to Tess's illness and the limited amount of time that she was wearing the activity monitor, however she gained most moderate activity from walking as part of her daily routine and activities with friends. She did not initially mention this in the interview and may not have recognised the contribution it may be making to her overall fitness. Her daily commitments limited her opportunities for exercise. At age 18, she has successfully transitioned to adult-level responsibilities for her exercise management, meeting her doctor's recommended goal of 30 minutes of activity per day.

Elaine. Elaine took early responsibility for managing her exercise. Her activities were mainly youth-led, but partly parent-led until the age of 16, and partly school based between the ages of 10-14. From age 16 onwards, all activities were youth-led. She attributed this to gaining her driver licence at this age. Elaine self-identified mainly strengths in her diabetes self-management and her current developmental status.

It was difficult to see many patterns in the data. Elaine's activity levels fluctuated depending on her club activities and non-recreational activity. She had injured herself during the week she wore the activity monitor, and reported being less active than usual. At age 22, she has successfully transitioned to adult-level responsibilities for her exercise management, meeting her doctor's advice of continuing her regular exercise schedule.

Raewyn. Raewyn described a successful transition from parent-led to adolescent-led exercise and took full responsibility for managing her exercise. She transitioned from mainly parent-led activities until the age of 16. At age 17, nearly all activity was school-based, but she took full responsibility for her diabetes from age 18 after she left school. For Raewyn, her health was perceived as a barrier to exercise and she took a year off physical activity while

she learnt to manage her diabetes, but has since resumed her activities. Raewyn identified both strengths and weaknesses in her diabetes self-management and her current developmental status.

It was difficult to see many patterns in the data due to Raewyn's schedule and the limited amount of time that she was wearing the activity monitor. For Raewyn, lack of time may have been perceived as a barrier to exercise. She spoke about some recent changes in her schedule that meant she had not been able to attend her regular exercise sessions, however she planned to resume them soon. She was also helping a family member on two days during the week which reduced her opportunities to exercise. Most of Raewyn's physical activity came from non-recreational activity. At age 24, Raewyn is in the process of meeting adult-level responsibilities for her exercise management; however she did not meet the generally recommended amount of 30 minutes per day.

Lucy. Lucy described a successful transition from parent-led to adolescent-led exercise and took full responsibility. She transitioned from mainly parent-led activities until the age of 16, with a transition through partly parent-led and partly youth-led from ages 16 to 18 until all activities from 19 onward were youth-led. Lucy felt this was due to gaining her driver licence and leaving school at the age of 18. Lucy identified both strengths and weaknesses in her diabetes self-management and her current developmental status.

Regarding Lucy's activity levels throughout the day, most activity on weekdays happened when as part of her daily activity and through non-recreational activity. In the weekend, much of her physical activity came from non-recreational activity and informal activities. Her daily commitments limited opportunities for exercise, as did her social commitments in the weekend. At age 24, Lucy has successfully transitioned to adult-level responsibilities for her exercise management, meeting the generally recommended goal of 30 minutes of activity per day.

Kelly. Kelly described a transition from parent-led to adolescent-led exercise, and took full responsibility for managing her exercise. She has transitioned from primarily parent-led with one school based activity until the age of 17, when responsibility was evenly split. At age 18, her activities were half parent-led and half youth-led. From ages 19-20 she reported only family-based planned activities, however all activities were youth-led by age 21. She left organised team sports when she was 15, and may have sought autonomy through time with peers away from adult supervision. She finished school sports when she finished school aged 17, and experimented with one type of informal activity but found it was not for her, until she began another informal activity aged 21 to improve her health. Kelly identified strengths and weaknesses in her diabetes self-management and her current developmental status.

It was difficult to see many patterns in the data due to Kelly's schedule. Her activity levels fluctuated throughout the week according to her work and other non-recreational activity but generally consisted of constant low-level activity. Lack of time was reported as a barrier to exercise and spending a day travelling to another city further reduced her opportunities to exercise. She was also restricting her usual weekend activities due to her health situation. At age 24, Kelly is meeting her doctor's recommended goal of getting low level exercise (such as walking) every day, and exercising continuously for at least 20 minutes at least three times a week.

Development of Autonomy for Exercise across the Group

Participants reported a range of ages when they became autonomous regarding exercise, which was defined as taking responsibility for their travel to and from sports and exercise activities. The changes in overall autonomy for exercise activities occurred both when there was a change in responsibility for transport for existing activities, such as participants driving themselves to activities where they were previously driven by parents.

Other changes occurred when participants began or ended activities that were parent, school or participant-led.

One interesting finding of the research concerns the type of exercise participants were most likely to continue with after leaving school. For some participants, it appeared that taking part in school-organised sports and activities did not necessarily lead to continued involvement after leaving school. On the other hand, it appeared more likely that participants would continue to attend sports and activities organised through an outside organisation after leaving school. This may be due to factors mentioned by participants as reasons for choosing that sport or method of exercise such as convenience and having friends present.

Another finding of the study regarding the development of responsibility for exercise behaviours, mentioned by several participants, was the impact of gaining their driver licence. Some participants mentioned that attending sports and activities required travel, and that they mainly travelled by car and were driven by parents. These participants reported that once they had obtained their driver licence they were no longer dependent on their parents for transport, and were able to take responsibility for their own transport to and from activities. They may have wanted to take responsibility for self-managing their sports activities earlier, but felt that this was not possible until they had obtained their driver licence. Some participants reported that their parents were also ready for them to take on this responsibility at the same time. However, participants became autonomous for different activities at different ages. When other family members were involved in the same exercise activities, participants were more likely to display low autonomy, that is, parents were more likely to take responsibility for transport. None of the participants mentioned cycling to activities and only one participant mentioned using the bus to travel to and from activities.

Participants reported various barriers to continued participation in exercise activities. When participants were asked why they quit sports or exercise activities, reasons given

included cost, lack of interest in the activity, too competitive, lack of free time (particularly as academic demands on time increased), not having friends involved, transport difficulties or inconvenience, feeling self-conscious or overexposed in uniforms during adolescence, no longer enjoying it and the interruption caused by ill health or injury. Conversely, reasons given by participants for taking part in activities included having a long-standing interest in it, friends or family members who took part in it, similarity to a previously enjoyed activity, taking part (particularly the gym) to improve fitness, and having fun. Although family involvement may have been sufficient to begin an activity, intrinsic motivation was important for participants to continue participating. Most participants reported starting an activity because a close family member was already involved. Some participants quit when their activities were no longer enjoyable, while others continued to enjoy their activities.

Daily diabetes tasks across the group. The differences between participants for daily diabetes tasks were relatively small. Tess completed the second highest, although she was the youngest of the participants, while Raewyn completed the fewest tasks. These results indicate that, in contrast to some of the literature, although this literature is based on the adolescent age range (Anderson et al., 1990; Hanna & Guthrie, 2003a; La Greca et al., 1990), in this group of young people, increasing age alone does not appear to increase responsibility for diabetes tasks. Additionally, Raewyn was one of the two most recently diagnosed, while Lucy had equally completed the most tasks, despite being diagnosed the longest. These results indicate that in contrast to the literature (Greening et al., 2007), in this group of young people, length of time since diagnosis does not appear to decrease adherence to daily diabetes tasks for these participants.

It should be noted that no participant reported checking urine for ketones the previous day. It is likely that this is because ketone testing is no longer recommended daily, and it is now recommended only when high blood glucose levels give cause for concern (Diabetes

New Zealand website, 2012). In light of this, the item should have been removed from the questionnaires. Additionally, four out of five participants reported that they had not made a record of their blood glucose levels the previous day. It may be that these participants were using blood glucose meters which automatically recorded this information, however this information was not obtained.

Nondaily diabetes tasks across the group. The differences between participants for nondaily diabetes tasks were also relatively small, and all participants completed these tasks to a high degree. This suggests that there is little difference between participants, and that there may be a ceiling effect, as participants' scores were at the upper end of the possible range. Elaine was one of the participants who had completed the most tasks, although she was the second youngest participant. In contrast to the literature (Anderson et al., 1990; Hanna & Guthrie, 2003a; La Greca et al., 1990), increasing age alone does not appear to increase responsibility for diabetes tasks.

Developmental tasks across the group. Regarding developmental tasks, there was a large difference in self-reported achieved tasks between the older participants and Tess. Her comparatively lower score is consistent with both the age gap between herself and the older participants and with the literature, with higher scores indicating higher levels of development and maturity with increasing age (Seiffge-Krenke, 1998; Steinberg & Silverberg, 1986). In contrast, Elaine was the second youngest of the participants but rated herself the highest of the group, therefore age was not the only factor affecting developmental status. She may have been exceptionally mature for her age, as she had consistently high self-ratings across the measures used in addition to early autonomy for self-management of exercise and high levels of physical activity throughout the week.

The pattern of self-ratings on the desired developmental subscale was similar to the achieved subscale, with Tess rating herself considerably lower than the others. Her answers

differed from the others as several tasks of future development were considered less important to her than to the older participants, as was the future development of tasks that she felt she had already achieved.

Current reported exercise and physical activity across the group. There was a wide range in self-reported days where incidental physical activity was performed over the previous week from one day to six days. The number of days where exercise was performed over the previous week ranged from one day to four days. For exercise advice given to participants by their healthcare team, responses included “no advice”, “continue with exercise schedule”, “moderate exercise three times per week” and “get low level exercise (such as walking) on a daily basis and exercise continuously for at least 20 minutes at least three times per week”.

The advice given varied considerably between participants, and may account for some of the differences in participants’ current exercise levels. The differing advice may reflect the lack of consistent guidelines regarding the recommended amount of exercise in people with T1D. The New Zealand Ministry of Health does not give general guidelines on exercise and physical activity for people with T1D and instead recommends that they receive individualised advice from their healthcare team (Ministry of Health website, 2014) while Diabetes New Zealand advises that people with T1D perform 30 minutes of moderate exercise every day (Diabetes New Zealand website, 2012). The lack of consistency in advice also illustrates one of the difficulties for health researchers when investigating adherence to healthcare advice, because unless participants were asked what advice they were given, it would not be possible to determine whether they were adhering to that advice from their current physical activity levels alone (Chimen et al., 2012; Toobert & Glasgow, 1994; Toobert et al., 2000).

Of equal concern is that two participants reported not receiving any advice about how often they should exercise. This may be the case, or alternatively, it is possible that participants were given this information but do not remember receiving it. One participant was diagnosed in early childhood, while another participant reported a similar lack of information given about diabetes self-management in general and exercise in particular.

Current exercise and physical activity measured by activity monitor across the group. Three of the five participants completed at least 30 minutes of moderate exercise daily as recommended by the Diabetes New Zealand website (2012), while another participant was completing the advice she was given by her clinician. There was considerable variation in participants' physical activity over the week. For the total number of hours of recorded activity, some differences can be explained by participants being busy and forgetting to put on the activity monitor. Additionally, there was a large variation in intensity of activity performed with only one participant recording activity levels in the very vigorous range, while the maximum activity level for other participants was moderate activity.

The activity monitor highlighted the importance of incidental physical activity, such as walking to and from a parked car or doing housework, compared to scheduled exercise sessions. For most participants, the most moderate intensity physical activity came from non-recreational activity such as housework or walking around rather than from planned exercise sessions. This is consistent with literature highlighting the importance of incidental exercise on general health (Badland & Schofield, 2005; Sallis, Bauman & Pratt, 1998). Increasing incidental physical activity throughout the day is also consistent with previous advice for adolescents with T1D (Robertson et al., 2009).

Activity monitor data also highlighted the role of paid work on levels of physical activity (Howley, 2001; Marshall, 2004; Sallis et al., 1998; van Domelen, 2011) although this was not included in analysis of the semi-structured interview. It was decided to focus on

information regarding participants' sports and exercise before, during and after adolescence for this study because the intentional aspect of taking part in exercise or physical activity is part of diabetes self-management. In this study, one participant reported being pleasantly surprised by the amount of physical activity recorded on the activity monitor throughout her work day and while walking as part of her daily routine, while other participants showed less sedentary activity while working than at other times. Participants also typically reported a larger range of activities during the interview than they were able to complete in the week they wore the activity monitor. However, it also highlighted additional activities not reported in the interview for some participants, which may have improved their overall levels of fitness.

Development of Exercise Autonomy and Relationship to Current Exercise Practice

Participants varied in both their current pattern of exercise and their pathways to autonomy during adolescence. For one participant, there was early autonomy for exercise, and was maintaining high levels of physical activity. Two participants achieved autonomy for exercise in adolescence and were also meeting current guidelines for physical activity, despite being sedentary for much of the day. One participant achieved autonomy after adulthood and was not meeting current recommended activity levels, but was meeting the recommendations of her clinician. One participant had previously achieved autonomy in adolescence but was not meeting current guidelines for physical activity. For some participants, their current pattern of exercise meets the recommended levels of exercise and they continue to maintain the autonomy they achieved during adolescence, while others are finding this more challenging.

There were a number of barriers to exercise reported by participants. Nearly all participants reported a lack of time a factor in being unable to exercise, or in ending an activity they had previously enjoyed. Some participants mentioned long commutes by car,

and for some, commitments to family and friends reduced their free time. Some participants reported a lack of access to nearby facilities to exercise, which was exacerbated by the earthquakes closing many facilities in Canterbury. Participants also may not have taken part in some activities due to the season or the weather, and the study was held at a busy time of year shortly after the Christchurch earthquakes, when people were under additional pressure. All participants reported that either in the past or now, their health was a barrier to exercise. For some this was a short-term injury or illness, others mentioned that it was their diabetes which had made them unwell. Several participants reported ending or suspending activities when they were first diagnosed with T1D.

Aside from diabetes, the barriers to exercise mentioned are also common to the wider population. Increased sedentary behaviour has been associated with broad societal changes such as increased commuting, desk-based jobs, labour-saving devices and using the television and computer as entertainment (Owen, Leslie, Salmon & Fotheringham, 2000). Changes can be made to increase physical activity at the population level (Sallis et al., 1998). These include urban design that is safe, clean, well-lit and that enhances walking or cycling as a mode of transport instead of commuting (Badland & Schofield, 2005; Wendel-Vos, Droomers, Kremers, Brug & van Lenthe, 2007). Public transport use should also be facilitated so that when walking or cycling is not practical, people can still access their preferred sport or activity. However, leisure facilities, local parks and accessible beaches are preferred (Giles-Corti & Donovan, 2002). To encourage physical activity, workplaces can make changes such as promoting stair use and making showers available to staff (Sallis et al., 1998). For adolescents in New Zealand, suggestions for overcoming barriers to exercise include peer involvement in exercise, making facilities and equipment easier to access and modifying PE classes to be more inclusive and reduce perceived social evaluation (Hohepa et al., 2006).

Support from friends, family and clinicians has been demonstrated to be a key predictor of adherence in young people with T1D (Kynäas & Rissanen, 2001). For one participant, who was diagnosed in early childhood, taking part in diabetes youth groups was very helpful. The groups included regular meetings and camps with other young people with T1D. Through the groups, she had developed a set of friends who were able to understand and support each other through the challenges of living with T1D. Conversely, another participant felt that lack of information about how to exercise safely was a barrier. She did not report accessing any kind of support, and was struggling to get adequate exercise. It is important that young people with T1D are encouraged to access both their existing support networks and support from diabetes sources to facilitate good health.

For some young people with T1D, individual support may be needed. There were some differences between self-perceptions of current levels of exercise and accelerometer recorded information. This is consistent with New Zealand research on differences between self-reported and recorded activity levels (Boon et al., 2008; Maddison, Foley, Olds, Ridley & Jiang, 2014; Newton et al., 2009) and with international research (Troiano et al., 2008). Although the week recorded may have been abnormal, nearly all participants reported performing more physical activity than was completed, and it is possible that participants may attend more to the times they exercise than the times they do not. When reflecting on their activity levels, participants may perceive that they regularly perform an ideal week of exercise, and may not remember the times that unforeseen circumstances prevent them from exercising. This is consistent with attribution theory, which describes how people use external factors to explain their behaviour (Heider, 2013/1958). Interventions that promote their autonomy may be needed to encourage behavioural change in young people with T1D with a gap between their ideal self and their behaviours. Motivational Interviewing has been

shown to increase the amount of exercise in adolescents with T1D overseas (Channon et al., 2007).

Limitations of the Research

Despite the efforts outlined above to improve the rigour of this qualitative study, there were some limitations to the research. These fell into four areas: difficulties with recruitment, technical limitations of the activity monitors and other measures used, individual participant information, and limitations of qualitative rigour.

Initially, there were difficulties with recruiting participants to the study. Possible reasons for this include the small population of the initially recruited age group, and associated factors such as increased mobility of emerging adults. The time of year is likely to have been a factor, as recruitment began towards the end of the academic year and included the lead-up to examinations, the examination period and the summer holiday period before the Christmas break. The setting of the current study may have contributed to recruitment difficulties. In the eighteen months to two years prior to recruitment, Christchurch experienced two major earthquakes which caused severe disruptions to infrastructure, housing, commercial and leisure activities, and which led to many residents migrating elsewhere. Many residents chose to leave after the second earthquake, including a large number of emerging adults, which is likely to have reduced the population eligible for the study (University of Canterbury, 2012; 2013).

Difficulties in recruitment led to changes in the research design. Initially, the age range of 18–20 was selected as it represented the transition period from the end of late adolescence to the beginning of emerging adulthood (Arnett, 2000). However this age range proved to be too limited and recruitment of participants was difficult, so the age range was expanded at a relatively late stage of recruitment. One limitation is the age range for the instruments used relative to the age range of the participants. Some of the instruments

selected for the study were originally intended for younger participants than those finally recruited. Because the instruments were designed to measure responses for adolescents, there was a ceiling effect for participants in this study as they were generally older and had higher levels of responsibility and autonomy than the adolescent participants from the original studies used to develop the instruments.

It should be noted that this study worked with a small number of participants who were all female. Ethnicity data was not collected to reduce the amount of identifiable data about participants, given the very small population, however the lack of ethnicity data is a limitation for transferability. Participants recruited were a convenience sample, which is a weaker sampling technique for ensuring saturation of the target population. It is possible that due to the self-selecting nature of recruitment, those recruited for the study may take more of an interest in physical activity than the general population of emerging adults with T1D. These factors influence the representativeness of the participants studied. However, describing these limitations enhances the transferability of this study's findings.

Next, there were potential limitations of the instruments used in the way that information was gathered and analysed. Limitations of the instruments used in the questionnaire include their intended use with a population younger than the participants in this study, therefore participants who did not live with their parents were unlikely to report parent involvement in daily tasks. From a psychological point of view, self-report measures are vulnerable to the social desirability bias, which occurs when participants answer questions the way they perceive the interviewer would like them to answer rather than according to their true beliefs (Crown & Marlowe, 1960; Furnham, 1986). In this study, participants may have anticipated the researcher seeking signs of autonomy and therefore rated themselves as having more autonomy and doing more exercise and physical activity over the previous week than was performed. Response bias may have affected participants'

narrative report of autonomy for travelling to sports and exercise during adolescence, where participants may have reported earlier independence, or omitted details of parent assistance in travelling to sports and exercise activities.

In this case, the construct “autonomy” was activated through cognitive processes by participants reading the information sheet and signing the consent form. Participants’ responses may also have been subject to errors of recall where they may have forgotten some of the sports and exercise activities they were involved in, particularly for those activities performed at a younger age. For example, one participant recalled additional activities at the second interview, and these activities were incorporated into her results. Additionally, some participants were unsure of the exact age they began or ended activities. Birthdays that fell partway through a school year may have made it more difficult for some participants to recall their exact age. Although qualitative research accepts that every person perceives the world according to their own biases and that different people may have competing but valid viewpoints, it also accepts that multiple information sources may be used to enhance credibility, (Spencer et al., 2010; Thomas & Magilvy, 2011). To reduce response bias and enhance credibility, another source such as parent report could have been used. However, because of the small scale of this study and its focus on asking emerging adults about autonomy, it was not considered either appropriate or practical to seek additional parent report information.

One limitation of using an accelerometer measuring counts is a lack of sensitivity to physical activity without changes in acceleration, including activities such as cycling or lifting weights. This means that activity levels recorded for such activities may have been underestimated (Boon et al., 2008). Conversely, the activity monitors detect motion while in a moving car, and one participant recorded activity during five hours of car travel, which is likely to have overestimated her total activity levels. Another limitation concerns the version

used of the Actigraph accelerometers and the *ActiLife* programme, both of which were lent by Lincoln University. At the time of the study, an older version of the Actigraph and *ActiLife* programme were used due to financial reasons, although newer versions were available. Additional information would have been obtained if the most recent Actigraph model and ActiLife software had been used, including triaxial data (measuring movement in three dimensions).

Activity monitor information may also have been affected by demand characteristics, when results are biased because participants are aware of being observed and consequently change their behaviour (Berthelot, Le Goff & Maugars, 2011; Orne, 1962). This includes the Hawthorne effect, when the knowledge by a participant that they are being observed leads to a change in their behaviour independent of any other variable. Participants were aware that their physical activity was being monitored by the activity monitor they were wearing and may therefore have increased the amount of exercise they performed during the week, meaning that their results did not represent a typical week. This may have been demonstrated by one participant who reported performing extra exercise in the evening because she was aware that she was wearing the activity monitor and had performed little physical activity. When I probed this comment, she said that she often did extra activity in the evenings when she felt she had not done enough exercise, reflecting a perception that the activity monitor played less of a role in her extra activity. Activity levels represent the week that was recorded, which may not be typical of participants' usual activity levels. Increased physical activity levels, if they occurred, may also have increased participants' chances of experiencing some of the risks associated with exercise in people with T1D such as hypoglycaemia.

Next, there were potential limitations on the information supplied by each participant. Two of the participants were diagnosed with T1D in childhood, while the other three were

diagnosed either during or after adolescence. This meant that neither they nor their families needed to be concerned about exercise in relationship to T1D before that age. For the present study, this means that until the point at which these participants were diagnosed, their development of autonomy in establishing regular exercise would have been that of a typically developing adolescent, rather than as an adolescent with a chronic condition where exercise was required as part of their self-care. However, information about their exercise patterns before their diagnosis is included, as it provides further information about their exercise history throughout childhood and early adolescence.

As mentioned previously, some participants were unwell, injured or had extra demands on them during the week they wore the activity monitor, therefore the information gained may not be of a typical week. Participants may not have been able to recall the details of all the activities they did since childhood equally, and this representation may underestimate the full scope of their activities. Likewise, participants who were unable to recall their activities during the week they wore the activity monitor may have wider range of activities than was reported here. Removing personal information about participants and their activities preserved confidentiality, although it has necessarily limited the amount and detail of possible discussion.

Next, some guidelines for rigour (Elliott et al., 2011) were challenging to meet within this study in terms of both appropriate methods and specification of methods. Changes to the design of the study part-way through meant that some instruments were designed to be used with younger participants and in a larger, quantitative study. Additionally, a true narrative interview method could not be used due to the detail of predetermined information sought about the transition process (Polkinghorne, 2000), nor was a systematic method such as grounded theory used to identify themes.

However, the interview skills I used were designed to probe for depth, including open-ended questions and prompts to elicit expanded answers, and gained valuable information. Decisions about data analysis were made in consultation with supervisors. I also demonstrated specification of methods by explaining the methods used and additional results in the appendices.

Another challenge of this study was situating the sample within the context. These included the convenience sampling technique used and the fact that all choosing to complete the study were female. Because of the small population of eligible participants, I prioritised confidentiality and therefore did not seek information about ethnicity or social class, while also anonymising the detail of activities. Despite these challenges, examining these factors serves to enhance transferability.

Implications of the Findings for Policy

Changes to policy may encourage young people to remain physically active by removing barriers to their participation. Significant barriers raised by participants to continuing with activities during adolescence included cost, transport and lack of time. Policy changes to support adolescents with T1D into remaining active include subsidising the costs of attending activities and ensuring that activities are available as locally as possible to minimise the need for transport. Additionally, several participants described reaching a point in their sport or activities where they felt unable to make the time commitment required to stay competitive, so instead they left the activity. Several participants described reaching this point when academic workloads increased and they had less free time. Policy changes may include the promotion of social-level activities in addition to competition-level activities to keep adolescents engaged in sports and activities rather than dropping out when they can no longer commit to competition-level activity.

In terms of current physical activity, emerging adults reported barriers to exercise including lack of time, lack of access to local facilities and health issues. Participants reported lack of time to exercise due to the demands on their time working, commuting and social commitments. Policy changes to enhance healthy lifestyles should promote urban planning that creates an environment conducive to exercise. In addition to promoting physical activity in the workplace, policy should also promote community access to open spaces, local facilities to exercise and access to childcare. For some people who may need more personalised assistance, policy should support individual therapy such as assertiveness training, problem-solving and cognitive-behavioural therapy, and Motivational Interviewing may help to increase physical activity in a way that promotes autonomy.

Implications of the findings for Care/Education

The findings of this study indicate that for these participants, sports and activities organised outside of school such as through clubs or other organisations may lead to an increased likelihood of continued participation after leaving school compared to sports organised in the school environment. To encourage long-term participation in sports, clinicians may consider whether this could apply to the young people in their care, and consider discussing the risks of stopping involvement in school-based sport after leaving school while promoting club-based sports and exercise as an alternative. However, school-based activities may be preferred by parents who have difficulties with transport or cost, or by adolescents who prefer exercising with school friends. For some, the convenience of school sports teams may override the future long-term benefits of independently organised activities while still providing the benefits of physical activity.

The findings of this study suggest that some young people and their families would benefit from clinical discussions about the adolescent's exercise regime and the benefits of performing exercise. Although adolescents may dislike refresher courses on basic diabetes

care (Spencer, Cooper & Milton, 2009) healthcare providers should not assume that information given once will be remembered and used correctly in multiple contexts which may change over time. In this study, two participants reported that their care plan had not covered exercise, while one of them reported that she did not feel educated regarding the correct way to calculate insulin doses and the effects of exercise on blood glucose levels. Given that diabetes management is complex, and adolescence is a period when hormonal and metabolic changes occur, making blood glucose regulation more difficult than in childhood or adulthood, it is recommended that adolescents and their parents receive periodic refresher education on more complex aspects of diabetes management including the benefits of regular exercise and physical activity.

Activity monitor information showed that for some of the young people in the study, paid work may result in extra physical activity. It is therefore important to raise awareness of the role played by paid work and incidental activity for emerging adults with T1D. Increasing awareness of the amount of physical activity they are performing outside of set exercise sessions may encourage them to include more physical activity during their work day to improve their health.

This study found that self-report methods of current levels of exercise may not be consistent with accelerometer-recorded activity levels, as participants in this study typically overestimated the amount of physical activity they performed over the past week. They also reported currently participating in sports or exercise activities during the interview which were not performed during the week wearing the activity monitor. Clinicians should be aware that self-reports may overestimate the amount of physical activity actually performed, and that when accuracy of information is important they may consider using a device such as an activity monitor as another information source.

Recommendations for Future Research

This study took a pragmatic approach to qualitative description, therefore the methodology incorporated facets of qualitative description, narrative interviewing and case studies while also incorporating information from self-report instruments and activity monitors. While this produced valuable information, future studies may extend this research using more traditional qualitative methods. On the other hand, the research has produced findings which larger scale studies may extend using quantitative methods.

Participants had some difficulty recalling activities performed during the week they wore the accelerometer. Although participants were aware that they would be wearing the activity monitor for one week and would then review their physical activity with the researcher, all participants had difficulty recalling some activities over the week when viewing the actigraphs. Some participants checked their diaries and phone messages to help them recall what they were doing at certain times. Future researchers using accelerometers may consider including an activity diary while wearing the activity monitor to improve recall of activities performed.

Another suggestion for further research concerns the instruments used. Due to the quantitative nature of the instruments used, they were less useful when used in single case research as they were designed to detect differences between groups rather than to describe individuals. It is recommended that future research uses or develops instruments which are standardised and to provide information about individuals. In particular, there appeared to be a dearth of suitable instruments assessing behavioural autonomy and future research in this area appears to be needed.

One area for another project to investigate is the discrepancy between reported and recorded levels of physical activity. Participants typically reported more physical activity and exercise sessions on the *SDSCA* than was recorded by the accelerometer. To some extent this

may be expected, particularly when seasonal activities are considered, however the differences were considerable for most participants. Participants who initially reported fewer physical activity and exercise sessions had a smaller discrepancy than other participants. Participants also reported taking part in a wider range of activities than was recorded by the activity monitor. These differences between self-perception and behaviours present another avenue for further investigation.

One major difficulty with this study was with recruitment from such a small population. Future research should ensure that when needing to use participants from such a small population, advance support for recruitment is gained from organisations with access to these populations.

Similar studies in the future should consider when the diagnosis was made. Three out of the five participants in this study were not diagnosed with T1D until during or after adolescence. This means that for participants diagnosed after the beginning of adolescence, participants' autonomy for exercise activities is likely to represent typical adolescent development rather than the development of an adolescent with a T1D who needs to consider exercise as part of a management plan. Future research intending to study the transfer of responsibility over adolescence should ensure that participants were diagnosed prior to the beginning of adolescence.

Due to the small scale of this study, no medical professional was included in the team. As there were ethical concerns about manipulating exercise levels in participants with T1D, particularly regarding the risk of inducing hypoglycaemia through exercise, this was an observational study gathering information about participants' current levels of physical activity for emerging adults and reported autonomy during adolescence. However, due to the Hawthorne effect it is possible that increased physical activity may have taken place, thereby increasing the potential risks of participants. It is recommended that future studies involving

adolescents and their families include a medical professional in order to mitigate these risks, to deal with any other concerns that may be raised such as the lack of diabetes knowledge raised by one participant, and to increase the range of research that can be performed.

Conclusion

The transfer of responsibility for T1D tasks during adolescence is a complex issue including different factors for every adolescent and family involved. This study investigated perceptions of autonomy development for exercise in emerging adults with T1D during adolescence, and current functioning regarding diabetes self-management and exercise. It was an observational study using a qualitative descriptive approach with an emphasis on rigour, on ethical practice and on preserving participants' confidentiality.

In this study, participants described their histories of developing autonomy for exercise, and although the pattern of transition for responsibility differed across participants, all participants achieved full autonomy. Additionally, participants reported and provided activity monitor data about their current levels of exercise and diabetes management, which reflected their current stages of development and lifestyle. Current levels of exercise and physical activity were examined and compared to guidelines for people with T1D.

A finding was that adolescents may be ready to take on responsibility for managing their exercise before they gain their driver licence, and other transport options should be encouraged. Encouraging sports and activities outside of the school environment may increase the likelihood of emerging adults continuing with activities after leaving school. Policies to promote physical activity should be encouraged to reduce the health burden of future diabetes complications. Further research on instruments measuring the behavioural autonomy of adolescents and emerging adults will benefit future studies of transition during adolescence, with the overall goal of improving adolescents' autonomy for exercise throughout adolescence and the rest of their adult lives.

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Appendix A.

Ethics

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Copy of Ethics Approval Letter



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2012/121

14 September 2012

Melinda McPherson
Health Sciences Centre
UNIVERSITY OF CANTERBURY

Dear Melinda

The Human Ethics Committee advises that your research proposal "The relationship between the development of autonomy in emerging adults aged 18-20 with Type 1 diabetes mellitus and self-management of their exercise routine: an exploratory study" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 7 September 2012.

We recommend that both the information sheet and consent form make it clear that the accelerometer is both expensive and lent by Lincoln University and that you are taking their telephone number and address so that you can collect it should anything get in the way of them returning it.

Best wishes for your project.

Yours sincerely

PP 

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

Approved Invitation

Health Sciences Centre

Title of study: "The relationship between the development of autonomy in emerging adults aged 18-24 with Type 1 Diabetes Mellitus and self-management of their exercise routine: An exploratory study"



Do you have Type 1 diabetes, and are between 18-24 years old?

We'd love to know what you think.

Hi, my name is Mindy McPherson, and my Master's project is to see how 18-24 year olds with Type 1 diabetes have learnt to manage their exercise routines over the years.

Fitting in regular exercise into a busy life can be a challenge, and we'd love to find out more about how that's been going for you. As part of the study, we will loan you an Actigraph accelerometer for a week so you can see how you are going. At the end of the week, you will be given two movie ticket vouchers as a thank you gift.

If you're between 18-24 years old with Type 1 diabetes, and you'd like to meet up for a hot drink (my treat) to find out more about taking part in the study, please email Mindy McPherson at mcm51@uclive.ac.nz

I hope to hear from you!



This project has been reviewed **and approved** by the University of Canterbury Human Ethics Committee.

Date posted:

Approved Information Sheet

Participant Information Sheet

Health Sciences Centre



Title: “The relationship between the development of autonomy in emerging adults aged 18-20 with Type 1 Diabetes Mellitus and self-management of their exercise routine: An exploratory study”

INFORMATION

You are invited to participate as a subject in the research project “The relationship between the development of autonomy in emerging adults aged 18-20 with Type 1 Diabetes Mellitus and self-management of their exercise routine: An exploratory study”.

The aim of this project is to find out more about the point in their lives when adolescents with Type 1 diabetes take control of their exercise routine, and what else was happening in terms of personal growth at that point in time.

Your involvement in this project will be to complete some questionnaires and an interview, which will take about an hour, and afterwards to wear an activity monitor for one week. At the end of the week, you will be given two movie ticket vouchers as a thank you gift. You will have the right to withdraw from the project at any time, including withdrawal of any information provided, without penalty.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: The identity of participants will not be made public without their consent. To ensure anonymity and confidentiality, your name will be kept completely confidential and all information about you will be stored securely until it is destroyed. We ask for your contact phone number and address only so that we can contact you if anything should prevent you from returning the activity monitor, which is being lent for this study by Lincoln University and which would be expensive to replace.

The project is being carried out in partial fulfillment for the degree of Master of Science in Child and Family Psychology by Mindy McPherson (email: mcm51@uclive.ac.nz) under the supervision of Kathleen Liberty, who can be contacted at 364 2545 and kathleen.liberty@canterbury.ac.nz. She will be pleased to discuss any concerns you may have about participation in the project.

The project has been reviewed *and approved* by the University of Canterbury Human Ethics Committee.

Approved Consent Form

Health Sciences Centre

Mindy McPherson

email: mcm51@uclive.ac.nz

cell: 0220670354

Waimairi Building

College of Education



September 2012

CONSENT FORM

The relationship between the development of autonomy in emerging adults with Type 1 Diabetes Mellitus and self-management of their exercise routine: an exploratory study

I have read and understood the description of the above-named project. On this basis I agree to participate as a subject in the project, and I consent to publication of the results of the project with the understanding that anonymity will be preserved.

I understand that I am being asked for my contact phone number and address only so that the researchers can contact me if anything should prevent me from returning the activity monitor, which is being lent for this study by Lincoln University and which would be expensive to replace.

I understand also that I may at any time withdraw from the project, including withdrawal of any information I have provided, without penalty.

I note that the project has been reviewed **and approved** by the University of Canterbury Human Ethics Committee.

NAME (please print):

Signature:

Date:

Approved Semi-structured Interview Questions

(W) (Warm up) Now I'm going to ask you some questions about what you did when you were growing up. To get started, think about back to when you were still at primary school. What kind of activities and hobbies did you do?

(WQ) (If queried)

1. Just think back to when you were in primary school, think about the sorts of things you used to do after school and in the weekends.

(WP) (Prompts)

1. Tell me about it.
2. Tell me some more about it.
3. And what else did you do?
4. And what else can you remember?
5. And what was that like?

(E) (Exercise question)

1. Now thinking back to when you were (10), tell me about all the sports or exercise you did at school. This could be anything that got your heart rate going.
2. Now think about all the sports or exercise you did outside of school when you were (10).

(EQ) (if queried)

1. Just think back to when you were about 10, in your last year of primary school, and try and remember what sports or exercise you used to do.
2. It could have been as part of an organised team or it could have been just you and your friends or family.

(EP) (Prompts)

1. Tell me (more) about it.
2. How long did you do it for?
3. When did you stop doing it?
4. Were there any changes in your life over time that led to you stopping?
5. Did you take up anything else when that stopped?
6. And what else did you do?
7. And what else can you remember?
8. And what was that like?
9. And how long was each session?
10. And how many times a week was it?
11. And what did you do in (summer/winter)?

(I) (Independence)

1. So you used to do (x, y & z) when you were (10). Think about (x). How did you usually get there and back?

(IQ) (If queried)

1. Just think about how you used to travel to and from practices and games. How did you use to get there?
2. Did you usually go there yourself, or did someone take you?

(IP) (Independence Prompts)

1. And how long did that usually take each way?
 2. And how many times a week was that?
- (repeat as needed for ages 10 through 20)*

(C) (Closing)

1. We're just about finished. Is there anything else I've missed that you think I should know?

Instructions for wearing the Actigraph activity monitor

- You should wear the Actigraph for 7 consecutive days, starting the morning after meeting with the researcher.
- Every morning, remember to put the Actigraph on as soon as you wake up or immediately after having a shower or bath, and take it off before you get into bed.
- The Actigraph can be worn underneath or on top of your clothing. Make sure the Actigraph has its lettering facing the right way up.
- Adjust the belt so that the Actigraph fits tightly but comfortably against your body.
- The Actigraph must not get wet. Please remove it for swimming and showering and cover it up in heavy rain.

Information about Type 1 Diabetes and Exercise from Diabetes New Zealand Website.

Retrieved May 2012 from:

http://www.diabetes.org.nz/living_with_diabetes/type_1_diabetes/physical_activity

Living well with diabetes

- Type 1 diabetes
 - Physical activity & Type 1 diabetes

Key points

- Most people find physical activity improves their feelings of wellness and vitality. It also helps in managing stress.
- Physical activity makes your body's cells more sensitive to the action of insulin.
- Your body remains more sensitive to insulin for up to 24 hours after physical activity. You may need to reduce your post physical activity insulin and / or eat more carbohydrate following physical activity.
- The key to managing physical activity safely with Type 1 diabetes is to monitor your blood glucose frequently and use this information to adjust your food and physical activity accordingly.
- Avoid injecting pre-physical activity insulin into any area of working muscle (it may get absorbed much more quickly than usual if you do).
- There are risks to physical activity. You should have a thorough medical check and consult with your diabetes specialist team before starting a physical activity routine.

Keeping up a physical activity schedule if you have Type 1 diabetes is an exciting challenge for your diabetes management skills. It helps if you start with a clear understanding of the interactions between insulin and physical activity. To begin with it is useful to understand how a person without diabetes uses glucose during physical activity.

How the body manages its glucose levels during physical activity in people without diabetes

During physical activity the muscles work harder and need more glucose to burn as energy. They pull glucose out of the bloodstream (blood glucose) as well as using up glucose that has been stored in the muscles (glycogen). Insulin works on the wall of the cell to allow glucose to get in.

During physical activity the muscle cells become more sensitive to the action of insulin. This means that the body doesn't need as much insulin to achieve the same job (moving either stored glucose or blood glucose into the muscle cells where it can get burned up). Because of this the body starts to gradually reduce its production of insulin.

After about 30 minutes of moderate physical activity the supply of glucose from the blood and from the stored glucose in muscles (glycogen) starts to run out. Blood glucose levels start to slightly drop. These slightly lowered blood glucose levels cause the body to change some hormone levels again. The hormone levels that it changes are insulin, glucagon and adrenaline. The body decreases the amount of insulin even further, and increases the amount of glucagon and adrenaline.

The change in these hormone levels then causes the body to do two things:

- To switch to using stored glucose from the liver
- To stimulate the liver to start making new glucose from stores of protein and fat

The end result is that although existing blood glucose and stored glucose (glycogen) in the muscles are used up, the body maintains a constant blood glucose level. This is because the body has changed its hormone levels, and by doing this, has turned the liver into a glucose factory. The liver releases its stored, or newly made glucose, into the bloodstream.

People who are able to make these hormone level changes automatically can conduct physical activity over prolonged periods (e.g. running a marathon) without any dramatic change in their blood glucose levels.

How the body uses glucose during physical activity if you have Type 1 diabetes

When you have Type 1 diabetes, your body cannot manufacture its own insulin. Therefore your body cannot (by itself) make the changes to insulin levels that are needed to keep your blood glucose level constant during physical activity.

Many people with Type 1 diabetes also have difficulty in adjusting the level of glucagon (another hormone) in their bodies. This is particularly so if they have had Type 1 diabetes for more than 5-8 years. Glucagon is a hormone your body makes to help bring your blood glucose level back up when it is low.

So, when you have Type 1 diabetes, your glucose use during physical activity is quite different from people who don't have Type 1. Your body does not have the ability to maintain your blood glucose levels at a constant rate automatically.

These main factors influence what happens to your blood glucose levels during physical activity:

- What your blood glucose is before and during physical activity
- How much injected insulin you have on board and when it is peaking
- How much and what type of carbohydrate food you have before and during physical activity
- The duration and intensity of your physical activity
- The level of circulating insulin will depend on the timing of your last insulin injection and the type of insulin used

Tips for exercising safely if you have Type 1 diabetes

If you are starting a physical activity or sporting programme, and you are new to managing your diabetes during physical activity, get help from your diabetes nurse educator or diabetes specialist before you start. Your diabetes team can help you plan how you adjust your insulin doses and food intake for physical activity.

If you have any complications of diabetes, including heart disease, retinopathy, neuropathy or kidney problems, see your diabetes team before planning a physical activity routine. Some forms of physical activity are safer than others when you have complications.

When you are starting out with a physical activity routine, start small and build up your fitness gradually. If you have been doing no physical activity, start with 5 - 10 minutes of moderate physical activity daily (e.g. brisk walking) and build this up by 5 minutes every 3 - 4 days until you are doing 30 minutes daily. Always conduct physical activity within your comfort zone. If you are out of breath, it is best to slow down until you are comfortable again.

Managing your blood glucose during physical activity

It is often not a safe choice to conduct physical activity at a time of day when your short-acting insulin is peaking. This is because physical activity makes you more sensitive to insulin. You are more likely to have low blood glucose if you physical activity when your short-acting insulin is peaking.

The best times to conduct physical activity are often:

- First thing in the morning before your breakfast short-acting insulin peak (but after a small carbohydrate snack - about 15-30 grams depending on the duration and intensity of physical activity planned)
- Or at the tail end of your breakfast short-acting insulin peak (before lunch but after a mid morning snack)
- Or the tail end of your lunchtime short-acting insulin peak (before evening meal but after a mid afternoon snack)

It is best to get advice from your diabetes team on your own specific insulin action times when planning physical activity. If you have to conduct physical activity at a time when your short-acting insulin is peaking (e.g. for a scheduled sports game) it pays to significantly reduce your pre-physical activity dose of insulin. Avoid injecting any pre-physical activity insulin into an area of working muscle.

Pre-physical activity blood glucose check?

Check your blood glucose before your physical activity. If you are organised enough it is a good idea to test your blood glucose twice before physical activity. Test 30 minutes before and again just before you begin. This way you will know whether your blood glucose level is stable or dropping. If it is dropping, you may need an extra carbohydrate snack before starting.

Pre-physical activity snack?

Your pre-physical activity blood glucose level will tell you if you need a snack before starting. The following chart provides a starting point only for how many grams of carbohydrate you may need. You will need to test and record your own blood glucose during and after physical activity to see if these quantities seem right for you.

Type of exercise	Pre-exercise blood glucose level less than 6mmol	Pre-exercise blood glucose level of 6-10 mmol	Pre-exercise blood glucose level of 10-15 mmol
Short duration (20-30 mins) of low-moderate intensity e.g., walking	25g CHO	0g CHO	0g CHO
Short duration high intensity (e.g., running, squash)	25g CHO	0g CHO	0g CHO
Moderate duration (45-60 mins) moderate intensity e.g., cycling, swimming	25 - 50g CHO	0 - 25g CHO	0g CHO
Long duration (60-75 mins) moderate intensity e.g., triathlon, soccer, football, jogging	50g CHO	25 - 50g CHO	25g CHO

Note: CHO is shorthand for carbohydrate.

Blood glucose higher than 15mmol/L?

If your pre-physical activity blood glucose is greater than 15mmol/L you should check your urine for ketones. If no ketones are present and your blood glucose has been falling, it is safe to physical

activity moderately – so long as you check your blood glucose often and stop physical activity if your blood glucose is climbing. If ketones are present it is best to rest, treat the blood glucose with short-acting insulin, drink plenty of low calorie fluids and delay physical activity for the day.

Carbohydrate during physical activity?

It pays to check your blood glucose about every 30 minutes when you are exercising. Most people seem to need about 50 - 60 grams of carbohydrate per hour during physical activity. This is often easiest taken as fruit juice, dried fruit, sports drink or as a dextrose gel pack (available at many sports shops).

Monitor, monitor, monitor . . .

Your best guide to managing your blood glucose levels during and after physical activity is to monitor your blood glucose levels frequently: before, during, and after physical activity. Keep a record of these along with how much you eat before and during physical activity. Also record the intensity and duration of the physical activity. Over time you will come to understand your body's usual response to physical activity.

It is more important to test your blood glucose level if you are trying a new form of physical activity. This will tell you how your blood glucose levels are responding to it. If you keep a record of your responses to different physical activity, this will help you over time.

Fluids

It is very important for all people to keep their fluid intake up during physical activity, but especially so for those with diabetes. When your blood glucose levels are even a little higher than the normal range, you are much more prone to dehydration. If you do get dehydrated, this can worsen high blood glucose levels.

Am I more prone to low blood glucose levels following physical activity?

Yes. Your body can remain much more sensitive to insulin for up to 24 hours following physical activity. Also during physical activity your body uses up its stores of glucose (from muscle and liver). For the next 10-24 hours your body will be replacing these stores and taking the extra glucose from your bloodstream.

For both these reasons you are much more prone to low blood glucose levels following physical activity. It pays to reduce the dose of insulin you take following physical activity. Your diabetes team can give you some pointers as to how much to reduce by. You may also need to take extra carbohydrate.

If you plan physical activity later in the day you will need extra carbohydrate at dinnertime. It is also wise to consider reducing your overnight insulin.

Over time, as you get established into a regular physical activity routine, you may find that your insulin doses throughout the day will need reducing. If you are getting frequent low blood glucose levels, or if you feel you are having to eat more food than you would like just to keep your blood glucose levels up, get help from your diabetes team to help you work out the best reductions to your dosages.

Safety issues

Because you are much more prone to having low blood glucose levels during or after physical activity, always carry some short-acting and some long-acting carbohydrate with you. Carry some

form of identification on you that shows that you have diabetes and are on insulin. It is often best to plan physical activity with another person. If you are exercising on your own, let someone know when you are expected back.

Remember to take special care of your feet when exercising. Your choice of shoes for physical activity is very important. If you are unsure as to what to buy consult a specialist shoe store or a podiatrist. Make sure you try your shoes on at the end of the day (when everyone's feet are a little more swollen than first thing in the day). And also when you are wearing thick sports socks. The socks you choose should be seamless, if possible. Shock absorbers fitted to your shoe are a plus.

Check your feet daily after physical activity. If you notice any problems, get help quickly. If you have any established foot problems it is best to plan a form of physical activity that does not expose your feet to high impact, e.g. cycling or swimming.

Information Given to Participant Expressing Lack of Knowledge About Diabetes Management and the Risk of Future Complications

Diabetes - type 1 - Complications

Description

An in-depth report on the causes, diagnosis, and treatment of type 1 diabetes.

Complications:

Type 1 diabetes reduces the normal lifespan by about 5 - 8 years. However, survival rates are improving in all ethnic groups and both genders. Longer survival rates are probably due to improvements in monitoring and tighter control of blood glucose. There are two important approaches to preventing complications from type 1 diabetes:

- Intensive control of blood glucose and keeping glycosylated hemoglobin (HbA1c) levels below 7%. This approach can help prevent complications due to vascular (blood vessel) abnormalities and nerve damage (neuropathy) that can cause major damage to organs, including the eyes, kidneys, and heart.
- Managing risk factors for heart disease. Blood glucose control helps the heart, but it is also very important that people with diabetes control blood pressure, cholesterol levels, and other factors associated with heart disease.

Diabetic Ketoacidosis

Diabetic ketoacidosis (DKA) is a life-threatening complication caused by insulin deficiency. For some, it may be the first sign that someone has diabetes. It may also occur in a person with type 1 diabetes who is not consistent with insulin therapy, or who has an acute illness or infection that makes their diabetes difficult to control. Other contributing factors are lack of health insurance and intentionally reducing insulin doses in order to lose weight, which occurs with adolescent girls in an effort to keep weight down.

Diabetic ketoacidosis often develops as follows:

- The process is usually triggered in insulin-deficient patients by a stressful event, most often pneumonia or urinary tract infections. Other triggers include alcohol abuse, physical injury, pulmonary embolism, heart attacks, or other illnesses.
- Severely low insulin levels cause excessive amounts of glucose in the bloodstream (hyperglycemia).
- Fat breakdown then accelerates and increases the production of fatty acids.
- These fatty acids are converted into chemicals called ketone bodies, which are toxic at high levels.

Symptoms and complications include:

- Nausea and vomiting
- Deep and rapid breathing may occur with frequent sighing
- Rapid heartbeat
- Severe dehydration
- Cerebral edema, or brain swelling, is a rare but very dangerous complication that occurs in 1% of ketoacidosis cases and results in coma, brain damage, or death in many cases.
- Other serious complications from DKA include aspiration pneumonia and adult respiratory distress syndrome.
- If the condition persists, coma and eventually death may occur, although over the past 20 years, death from DKA has decreased to about 2% of all cases.

Life-saving treatment uses rapid replacement of fluids with a salt (saline) solution followed by low-dose insulin and potassium replacement.

Ketoacidosis is a serious condition of glucose build-up in the blood and urine. A simple urine test can determine if high ketone levels are present.

Hypoglycemia

Tight blood sugar (glucose) control increases the risk of low blood sugar (hypoglycemia). Hypoglycemia occurs if blood glucose levels fall below normal. It is generally defined as a blood sugar below 70 mg/dL, although this level may not necessarily cause symptoms in all patients. Insufficient intake of food and excess exercise or alcohol intake may cause hypoglycemia. Usually the condition is manageable, but, occasionally, it can be severe or even life threatening, particularly if the patient fails to recognize the symptoms, especially while continuing to take insulin or other hypoglycemic drugs.

Risk Factors for Severe Hypoglycemia. Among young patients, the youngest children and boys of any age are at higher risk for hypoglycemia. Specific risk factors for severe hypoglycemia include:

- Patients attempting tight control of blood glucose and HbA1c levels
- Long-term diabetes
- Patients who do not comply with treatment
- Infections such as gastroenteritis or respiratory illnesses

Hypoglycemia unawareness. Hypoglycemia unawareness is a condition in which people become accustomed to hypoglycemic symptoms. They may no longer notice the signs of hypoglycemia until they become more severe. It affects about 25% of patients who use insulin, nearly always people with type 1 diabetes. In such cases, hypoglycemia appears suddenly, without warning, and can escalate to a severe level. Even a single recent episode of hypoglycemia may make it more difficult to detect the next episode. With vigilant monitoring and by rigorously avoiding low blood glucose levels, patients can often regain the ability to sense the symptoms. However, even very careful testing may fail to detect a problem, particularly one that occurs during sleep.

Symptoms. Mild symptoms usually occur at moderately low and easily correctable levels of blood glucose. They include:

- Sweating
- Trembling
- Hunger
- Rapid heartbeat

Severely low blood glucose levels can cause neurologic (brain and nerve) symptoms, such as:

- Confusion
- Weakness
- Disorientation
- Combativeness
- In rare and worst cases, coma, seizure, and death

Heart Disease and Stroke

Patients with type 1 diabetes are 10 times more at risk for heart disease than healthy patients. Heart attacks account for 60% of deaths in patients with diabetes, while strokes account for 25% of such deaths. Diabetes affects the heart in many ways:

- Both type 1 and 2 diabetes accelerate the progression of atherosclerosis (hardening of the arteries). Diabetes is often associated with low HDL ("good" cholesterol) and high triglycerides. This can lead to coronary artery disease, heart attack, or stroke.
- In type 1 diabetes, high blood pressure (hypertension) usually develops if the kidneys become damaged. High blood pressure is another major cause of heart attack, stroke, and heart failure. Children with diabetes are also at risk for hypertension.
- Impaired nerve function (neuropathy) associated with diabetes also causes heart abnormalities.

Atherosclerosis is a disease of the arteries in which fatty material is deposited in the vessel wall, resulting in narrowing and eventual impairment of blood flow. Severely restricted blood flow in the arteries to the heart muscle leads to symptoms such as chest pain. Atherosclerosis shows no symptoms until a complication occurs.

Kidney Damage (Nephropathy)

Kidney disease (nephropathy) is a very serious complication of diabetes. With this condition, the tiny filters in the kidney (called glomeruli) become damaged and leak protein into the urine. Over time this can lead to kidney failure. Urine tests showing microalbuminuria (small amounts of protein in the urine) are important markers for kidney damage.

Diabetic nephropathy, the leading cause of end-stage renal disease (ESRD), occurs in about 20 - 40% of patients with diabetes. Patients with ESRD have 13 times the risk of death compared to other patients with type 1 diabetes. If the kidneys fail, dialysis is required. Symptoms of kidney failure may include swelling in the feet and ankles, itching, fatigue, and pale skin color. The outlook of end-stage renal disease has greatly improved during the last four decades for patients with type 1 diabetes, and fewer people with type 1 diabetes are developing ESRD.

Neuropathy

Diabetes reduces or distorts nerve function, causing a condition called neuropathy. Neuropathy refers to a group of disorders that affect nerves. The two main types of neuropathy are:

- *Peripheral* (affects nerves in the toes, feet, legs, hand, and arms)
- *Autonomic* (affects nerves that help regulate digestive, bowel, bladder, heart, and sexual function)

Peripheral neuropathy particularly affects sensation. It is a common complication that affects nearly half of people with type 1 or type 2 diabetes after 25 years. The most serious consequences of neuropathy occur in the legs and feet and pose a risk for ulcers and, in unusually severe cases, amputation. Peripheral neuropathy usually starts in the fingers and toes and moves up to the arms and legs (called a stocking-glove distribution). Symptoms include:

- Tingling
- Weakness
- Burning sensations
- Loss of the sense of warm or cold
- Numbness (if the nerves are severely damaged, the patient may be unaware that a blister or minor wound has become infected)
- Deep pain

Autonomic neuropathy can cause:

- Digestive problems (constipation, diarrhea, nausea, vomiting)
- Bladder infections and incontinence
- Erectile dysfunction

- Heart problems. Neuropathy may mask angina, the warning chest pain for heart disease and heart attack. Patients with diabetes should be aware of other warning signs of a heart attack, including sudden fatigue, sweating, shortness of breath, nausea, and vomiting.
- Rapid heart rates
- Light-headedness when standing up (orthostatic hypotension)

Blood sugar control is an essential component in the treatment for neuropathy. Studies show that tight control of blood glucose levels delays the onset and slows progression of neuropathy. Heart disease risk factors may increase the likelihood of developing neuropathy. Lowering triglycerides, losing weight, reducing blood pressure, and quitting smoking may help prevent the onset of neuropathy.

Foot Ulcers and Amputations

About 15% of patients with diabetes experience serious foot problems. They are the leading cause of hospitalizations for these patients. The consequences of both poor circulation and peripheral neuropathy make this a common and serious problem for all patients with diabetes.

Diabetes is responsible for more than half of all lower limb amputations performed in the U.S. Each year there are about 88,000 non-injury amputations, 50 - 75% of them due to diabetes. About 85% of amputations start with foot ulcers, which develop in about 12% of people with diabetes.

People with diabetes who are overweight, smokers, and have a long history of diabetes tend to be at most risk. People who have the disease for more than 20 years and are insulin-dependent are at the highest risk. Related conditions that put people at risk include peripheral neuropathy, peripheral artery disease, foot deformities, and a history of ulcers.

In general, foot ulcers develop from infections, such as those resulting from blood vessel injury. Numbness from nerve damage, which is common in diabetes, compounds the danger since the patient may not be aware of injuries. About one-third of foot ulcers occur on the big toe.

Charcot Foot. Charcot foot or Charcot joint (medically referred to as neuropathic arthropathy) occurs in up to 2.5% of people with diabetes. Early changes appear similar to an infection, with the foot becoming swollen, red, and warm. Gradually, the affected foot can become deformed. The bones may crack, splinter, and erode, and the joints may shift, change shape, and become unstable. It typically develops in people who have neuropathy to the extent that they cannot feel sensation in the foot and are not aware of an existing injury. Instead of resting an injured foot or seeking medical help, the patient often continues normal activity, causing further damage.

Charcot foot is initially treated with strict immobilization of the foot and ankle; some centres use a cast that allows the patient to move and still protects the foot. When the acute phase has passed, patients usually need lifelong protection of the foot using a brace initially and custom footwear.

Retinopathy and Eye Complications

Diabetes accounts for thousands of new cases of blindness annually and is the leading cause of new cases of blindness in adults ages 20 - 74. The most common eye disorder in diabetes is retinopathy. People with diabetes are also at higher risk for developing cataracts and certain types of glaucoma.

Retinopathy. Retinopathy is a condition in which the retina becomes damaged. The two primary abnormalities that occur are a weakening of the blood vessels in the retina and the obstruction in the capillaries -- probably from very tiny blood clots. Retinopathy generally occurs in one or two phases:

- The early and more common type of this disorder is called *nonproliferative or background retinopathy*. The blood vessels in the retina are abnormally weakened. They rupture and leak,

and waxy areas may form. If these processes affect the central portion of the retina, swelling may occur, causing reduced or blurred vision.

- If the capillaries become blocked and blood flow is cut off, soft, "woolly" areas may develop in the retina's nerve layer. These woolly areas may signal the development of *proliferative retinopathy*. Often there are no symptoms of progressing retinopathy. In this more severe condition, new abnormal blood vessels form and grow on the surface of the retina. They may spread into the cavity of the eye or bleed into the back of the eye. Major hemorrhage or retinal detachment can result, causing severe visual loss or blindness. The sensation of seeing flashing lights may indicate retinal detachment.

All patients with diabetes should begin having a professional eye exam according to the following schedule:

- Children older than 10 years and with diabetes for at least 3 - 5 years
- Adolescents and adults with type 1 diabetes, within 5 years of diagnosis
- Adults with type 2 diabetes soon after diagnosis is made

After the first exam, most patients should have a yearly eye examination. Patients with no signs of retinal damage or low risk factors for retinopathy may only require screening every 2 - 3 years. Patients beginning a new or vigorous exercise program should have their eyes examined, as well as all patients planning pregnancy.

Infections

Respiratory Infections. People with diabetes face a higher risk for influenza and its complications, including pneumonia, possibly because the disorder neutralizes the effects of protective proteins on the surface of the lungs. Everyone with diabetes should have annual influenza vaccinations and a vaccination against pneumococcal pneumonia.

Urinary Tract Infections. Women with diabetes face a significantly higher risk for urinary tract infections, which are likely to be more complicated and difficult to treat than in the general population.

Depression

Diabetes doubles the risk for depression. Depression, in turn, may increase the risk for hyperglycemia and complications of diabetes.

Osteoporosis

Type 1 diabetes is associated with a slightly reduced bone density, putting patients at risk for osteoporosis and possibly fractures.

Other Complications

Diabetes increases the risk for other conditions, including:

- Hearing loss
- Periodontal disease
- Carpal tunnel syndrome and other nerve entrapment syndromes
- Nonalcoholic fatty liver disease, also called nonalcoholic steatohepatitis (NASH); a particular danger for people who are obese
- Colorectal cancer
- Uterine cancer

Specific Complications in Women

Diabetes can cause specific complications in women. Women with diabetes have an increased risk of recurrent yeast infections. In terms of sexual health, diabetes may cause decreased vaginal lubrication, which can lead to pain or discomfort during intercourse.

Women with diabetes should also be aware that certain types of medication can affect their blood glucose levels. For example, birth control pills can raise blood glucose levels. Long-term use (more than 2 years) of birth control pills may increase the risk of health complications.

Diabetes and Pregnancy. Pregnancy in a patient with existing diabetes can increase the risk for birth defects. Studies indicate that high blood sugar levels (hyperglycemia) can affect the developing fetus during the critical first 6 weeks of organ development. Therefore, it is important that women with pre-existing diabetes (both type 1 and type 2) who are planning on becoming pregnant strive to maintain good glucose control for 3 - 6 months before pregnancy.

It is also important for women to closely monitor their blood sugar levels during pregnancy. For women with type 1 diabetes, pregnancy can affect their insulin dosing needs. Insulin dosing may also need to be adjusted during and following delivery. [For more information, see “Treatment of Diabetes During Pregnancy” in *Treatment of Complications* section of this report.]

Diabetes and Menopause. The changes in estrogen and other hormonal levels that occur during perimenopause can cause major fluctuations in blood glucose levels. Women with diabetes also face an increased risk of premature menopause, which can lead to higher risk of heart disease.

Specific Problems for Adolescents with Type 1 Diabetes

Lack of Blood Glucose Control. Control of blood glucose levels is generally very poor in adolescents and young adults. Adolescents with diabetes are at higher risk than adults for ketoacidosis resulting from noncompliance. Young people who do not control glucose are also at high risk for permanent damage in small vessels, such as those in the eyes.

Eating Disorders. Up to a third of young women with type 1 diabetes have eating disorders and under-use insulin to lose weight. Anorexia and bulimia pose significant health risks in any young person, but they can be especially dangerous for people with diabetes.

Resources

- www.diabetes.org -- American Diabetes Association
- www.niddk.nih.gov -- National Institute of Diabetes and Digestive and Kidney Diseases
- www.jdrf.org -- Juvenile Diabetes Research Foundation
- www.nei.nih.gov -- National Eye Institute
- www.eatright.org -- American Dietetic Association
- www.kidney.org -- National Kidney Foundation
- www.diabetestrialnet.org -- Type 1 Diabetes International Clinical Trial Net
- www.medicalert.org -- Bracelets or neck chain emblems with personal medical information
- www.childrenwithdiabetes.com -- Children with diabetes online community

Appendix B.

Results

Figures

Summary of Physical Activity over a week across Participants as Percentage of Activity

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Tess

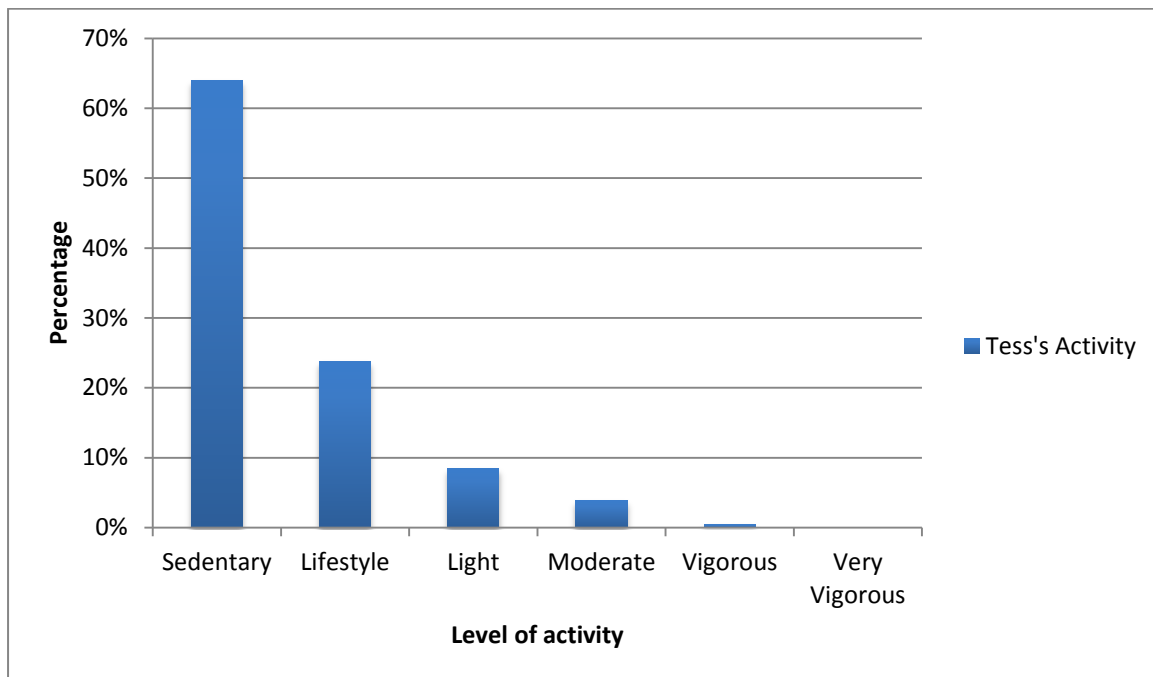


Figure B1. Summary of Tess' physical activity levels from actigraph monitoring for six days out of a week

Elaine

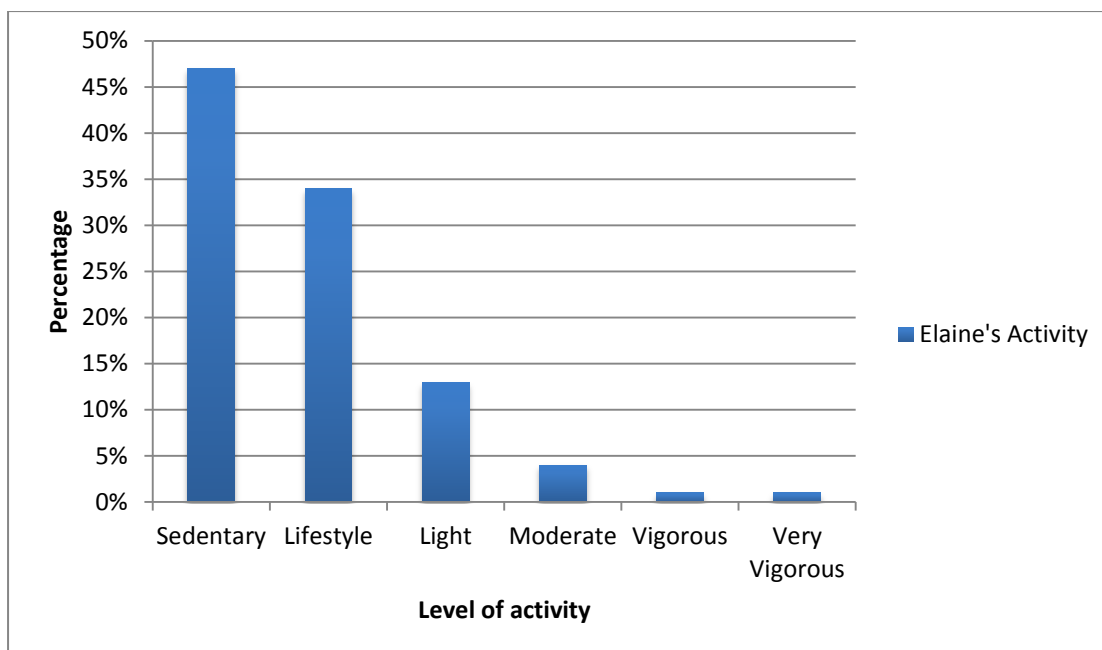


Figure B2. Summary of Elaine's physical activity levels from Actigraph monitoring for a week

Raewyn

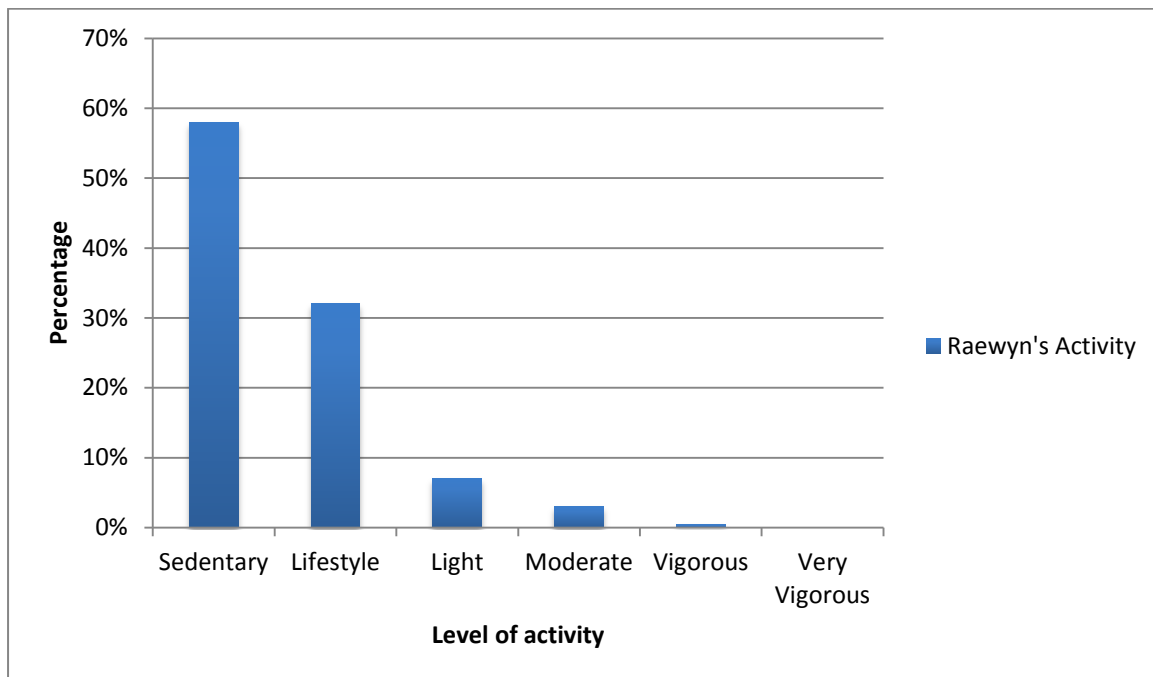


Figure B.3 Summary of Raewyn's physical activity levels from Actigraph monitoring for six days out of a week

Lucy

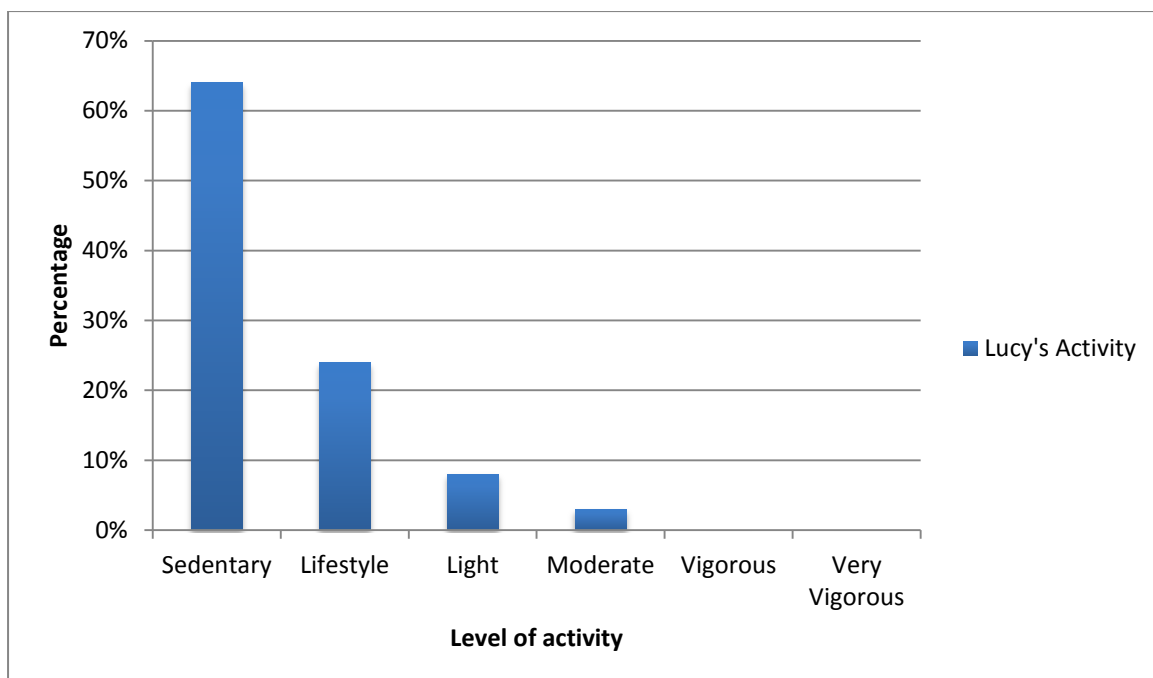


Figure B.4 Summary of Lucy's physical activity levels from Actigraph monitoring for a week

Kelly

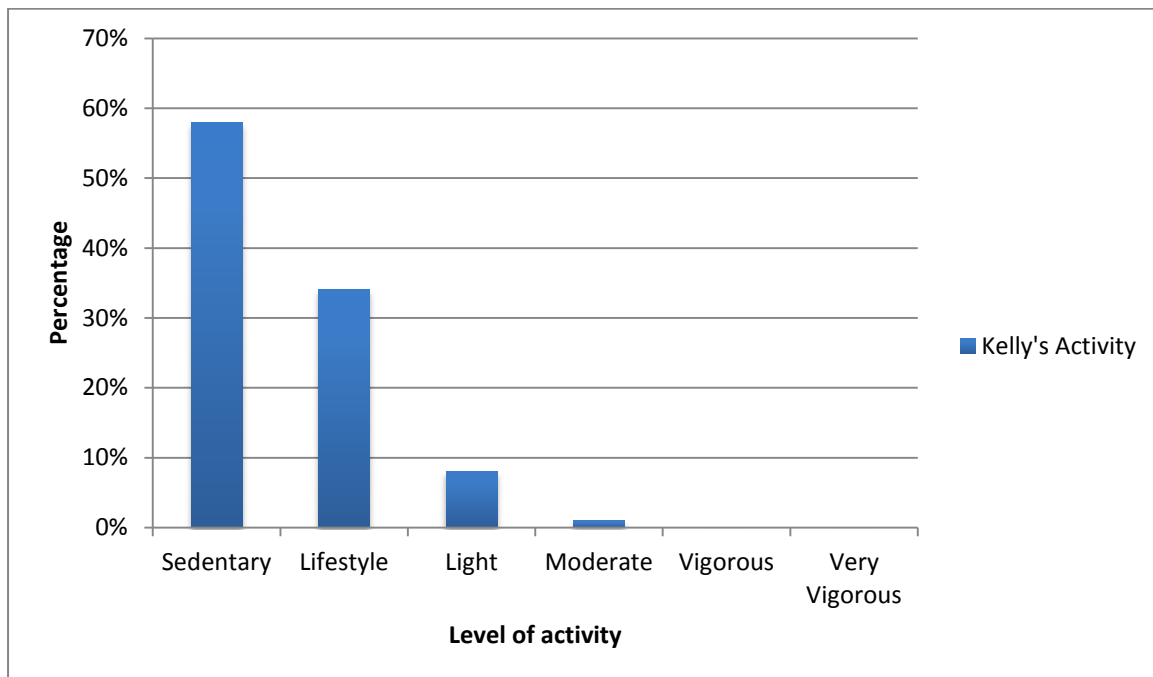


Figure B.5 Summary of Kelly's physical activity levels from actigraph monitoring for a week

All participants

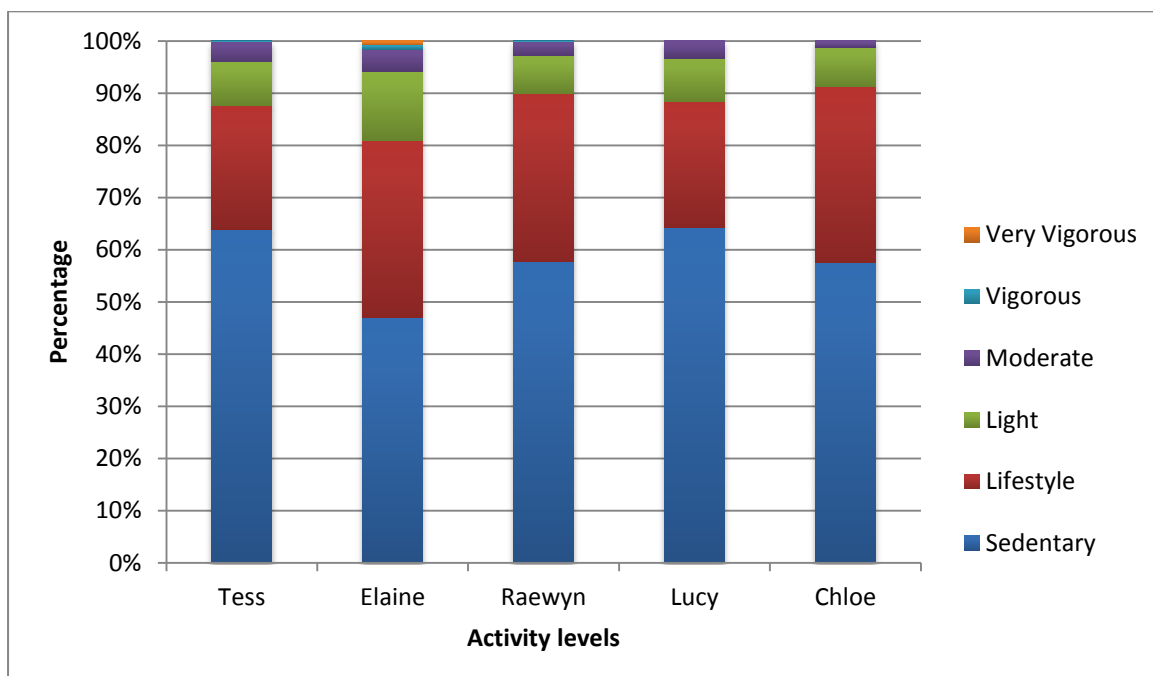


Figure B.6 Mean intensity of activity levels over a week across participants as a percentage of the total

All participants

Participant	Tess		Elaine		Raewyn		Lucy		Kelly	
Age	18		22		24		24		24	
	Minutes	%	Minutes	%	Minutes	%	Minutes	%	Minutes	%
Activity level										
Sedentary	2706	63.9%	2819	47.1%	2826	57.7%	3816	64.3%	3509	57.5%
Lifestyle	1008	23.8%	2031	33.9%	1580	32.2%	1429	24.1%	2056	33.7%
Light	355	8.4%	794	13.3%	359	7.3%	498	8.4%	462	7.6%
Moderate	164	3.9%	252	4.2%	132	2.7%	195	3.3%	73	1.2%
Vigorous	3	0.1%	49	0.8%	3	0.1%	0	0.0%	0	0.0%
Very Vigorous	0	0.0%	44	0.7%	0	0	0	0.0%	0	0.0%
Total minutes	4236		5989		4900		5938		6100	

Table B.1. Intensity level of activity across participants over a week across participants