THE ROLE OF ONLINE SUPPORT GROUPS FOR PARENTS OF ADOLESCENTS WITH TYPE 1 DIABETES DURING THE TRANSITION TO ADULT DIABETES SERVICES.

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Abstract

Paediatric type 1 diabetes is often referred to as a 'family disease' due to the importance of family interactions and parental supervision required to achieve optimal blood glucose levels and quality of life. The treatment regime for this chronic disease in children is complex and requires co-management by parents, many of whom experience psychosocial problems whilst undertaking this responsibility. Parents managing their child's diabetes care need informational and emotional support that is not always adequately met by existing sources of support. With Internet access becoming increasingly ubiquitous, parents can search online for health information, advice and support, augmented by the use of diabetes online support groups. Previous research has identified potential benefits health-related online support groups can afford patients with chronic health conditions; addressing their information and support needs in a safe, non-judgemental environment with others in a similar situation, shown to empower individuals. However, little is known about the role of diabetes online support groups for parents of children with type 1 diabetes as they transition from paediatric to adult diabetes services during late adolescence; a particularly stressful event for some parents. The present thesis aimed to address this disparity by exploring parents of adolescent's experiences of using diabetes online support groups during a period of change; investigating if group membership affects psychological well-being and if participation empowers parents. Using a mixed methods approach, three empirical studies were conducted. The first study used an online survey completed by 88 parents. This garnered information about parents' experiences of using diabetes online support groups. It assessed the illness representations held about diabetes, along with reported levels of parental diabetes distress. Perceptions of empowering processes and outcomes within the diabetes online support groups were also investigated. For Study 2, qualitative one-to-one interviews were carried out with 13 parents who had previously completed the online survey, to gain a greater understanding of parents' initial motivation to join a diabetes online support group, and what factors influence their continued participation. The final study was a thematic analysis of 945 messages posted on two UK diabetes online support groups to identify and examine the types of social support in group members’ communications. The combined results from the three studies indicate diabetes online support groups play an important role in providing informational and emotional support to parents of adolescents with type 1 diabetes. Furthermore, the availability and reciprocity of social support within diabetes online group were considered empowering by parents, with positive psychosocial benefits noted as being associated with group membership rather than dependant on the level of participation. Findings from this thesis also identified a disparity between mothers and fathers using diabetes online support groups, suggesting a more targeted approach should be considered for future research to investigate fathers’ perspectives and experiences. This thesis provides a deeper understanding of issues pertinent to the use of diabetes online support groups by parents of adolescents with type 1 diabetes. It provides a unique insight into the implications and potential benefits diabetes online support groups can have for the psychological well-being of parents for whom relinquishing control of their child’s diabetes management may be a determinant of increased anxiety, fear and diabetes distress.

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Table of Contents

Chapter 3: Online communities and support groups 47

Chapter 5: Study 1 - Exploring how parents of adolescents use diabetes online support groups: Results from an online survey 117

Chapter 8: Discussion 253

List of Tables

List of Figures

List of Appendices

Chapter 1: Introduction

1.1 Introduction

People are increasingly turning to the Internet to search for health-related information. Figures published by The Office for National Statistics (ONS) showed in January 2020, 96% of UK households had Internet access, with 93% of adults reporting they had recently used the Internet at least weekly, if not daily (Office for National Statistics 2020). Furthermore, the number of UK adults going online to search for health-related information rose from 43% in 2013 to 63% in 2019 (Office for National Statistics 2019), suggesting the Internet is rapidly becoming established as a central source of health information for many. Not only are people able to use the Internet as a resource to find health information about a variety of illnesses and conditions, but also as a medium that allows them to search for and connect with others affected by a similar condition, through the use of health-related online support groups (Eysenbach et al 2004). For the purpose of this thesis, health-related online support groups are considered to be a type of virtual community that provides a dynamic online environment where individuals with similar concerns and experiences can exchange information, advice or social support within the group (Coulson and Smedley 2015).

The exponential growth of health-related online support groups has led to a proliferation of research that has investigated how individuals with chronic conditions and their caregivers use these groups to be better informed about the condition, share information and personal experiences, and obtain social support (Algtewi, Owens and Baker 2015, Bussone, Stumpf and Wilson 2017, Coulson 2005, Coulson, Buchanan and Aubeeluck 2007, Coursaris and Lui 2009, Loader et al 2002, Loane and D'Alessandro 2013). In addition, researchers have reported patients and caregivers feeling empowered from participating in health-related online support groups (Aardoom et al 2014, Campbell, Coulson and Buchanan 2013, Glenn 2015, Kirk and Milnes 2016, Mo and Coulson 2010, van Uden-Kraan et al 2008).

For parents of a child diagnosed with type 1 diabetes they are initially expected to manage or co-manage a complex clinical regime necessary to keep their child alive and mitigate the risk of diabetic complications. A substantial amount of information needs to be disseminated in order to carry this out successfully and the level of understanding and commitment required is high. Research investigating parental experiences and responses to having a child diagnosed with type 1 diabetes identified high levels of parental anxiety, chronic sorrow and emotional distress (Bowes et al 2009, Haugstvedt et al 2010, Kovacs et al 1985, Rankin et al 2014, Streisand et al 2008). The emotional, psychological and practical impact of parenting a child with diabetes continues to be reported by parents' years after diagnosis and into adolescence (Buckloh et al 2008, Hessler et al 2016, Jaser, Linsky and Grey 2014, Law et al 2013, Whittemore et al 2012). For some parents, the concerns and fears about diabetes appear as prescient as when they first received their child's diagnosis.

The Diabetes Transition Service Specification guidelines published by the NHS (2016) support the premise that adolescents with diabetes be encouraged to become more responsible for their diabetes management, aiming to achieve clinical autonomy from parents and caregivers. Whilst the guidelines suggest the needs of parents be taken into account during the transition period from paediatric to adult diabetes services, recommendations for actioning this are not specified. During this period of change, parents may feel excluded from their child's healthcare, leading to a discontinuity of information that relates to diabetes. They too may be facing different challenges whilst relinquishing co-management of their child's diabetes, but still require information and support (Allen et al 2011). Previous research demonstrates adults with diabetes benefit from using online support groups, acquiring informational and experiential information (Gilbert et al 2012, Hilliard et al 2015, Oh and Lee 2012). Likewise, it has been reported that parents of young children with diabetes value the informational and emotional support they find in diabetes online groups, particularly following diagnosis, at the start of their diabetes journey (Balkhi et al 2014, Merkel and Wright 2012). However, relatively little is known about the experiences of parents of adolescents with type 1 diabetes who are members of diabetes online support groups during what may be a period of significant change.

1.2 Research aims and objectives

The overarching aim of this thesis was to gain a greater understanding of the way parents of adolescents with type 1 diabetes use diabetes specific online support groups. The objectives were as follows:

- To consider how and why parents of adolescents with type 1 diabetes use health-related online support groups during the transition from paediatric to adult diabetes services.
- To gain an understanding of the motivations for using these online support groups.
- To consider if using health-related online support groups may empower individuals affected by type 1 diabetes and the consequences of this.
- To explore the impact health-related online support groups has on parental psychological well-being during this period of transition.

1.3 Contribution of the research

Whilst the role and potential benefits of engaging in health-related online support groups for patients and carers affected by a variety of chronic conditions has been investigated, the online experiences of parents of an adolescent with type 1 diabetes is under-researched. This thesis therefore aims to present a unique insight into how and why this cohort chooses to engage with a diabetes online support group, and the impact and effect of participation.

1.4 Thesis structure

The overall structure of this thesis comprises eight chapters, including this introductory chapter. Chapter 2 presents an overview of diabetes, including the epidemiology and aetiology of type 1 diabetes, and acute and chronic diabetic complications. To give context to the thesis, the developmental stage of adolescence is defined and the impact of diabetes on both adolescents and parents is considered, with particular attention paid to the psychosocial challenges these parents face. Chapter 3 reviews relevant literature pertaining to health-related online support groups. The unique characteristics of online support groups are examined, along with potential advantages and disadvantages. The motivations for joining an online support group, user characteristics and levels of participation are also addressed. The final part of this chapter looks at the benefits of engaging in online support groups.

The rationale for using a mixed methods approach to meet the research aims of this thesis is presented in Chapter 4. Details of the philosophical underpinnings of the research and pragmatist approach chosen are discussed. This is followed by details of the methods used for the three empirical studies, acknowledging the advantages and disadvantages of each. Finally, the ethical considerations of online research are considered, with details of the ethical guidelines adopted for the purpose of this thesis.

Chapters 5, 6 and 7 describe the empirical studies carried out for this thesis. Each chapter details the rationale of the study, the aims and objectives, the method employed, and the subsequent results. The findings are then discussed, along with any limitations of the study and recommendations for future research. Chapter 5 presents details of an online survey completed by participants recruited from diabetes online support groups. Designed to gauge information about their Internet use, and group membership, the survey also explored the illness perceptions participants held regarding diabetes, and their levels of diabetes distress. Empowering processing and outcomes from participating in diabetes online support groups were similarly considered. Chapter 6 is a qualitative study that used one-to-one telephone interviews with participants who had previously completed the online survey discussed in Chapter 5. Building on findings from the online survey, the aim of the second empirical study was to explore the motivations of parents for joining a diabetes online support group in the first instance and to gain an understanding about what influences continued participation, and the benefits thereof. Chapter 7 presents a thematic analysis of messages posted to diabetes online support groups to assess the dimensions of social support available. As part of the triangulated methodological approach adopted in this thesis, the third empirical study helps provide a deeper, richer insight into the role diabetes online support groups have for parents of adolescents.

Chapter 8 is the final overall discussion chapter. It draws upon the entire thesis, bringing together the various theoretical and empirical strands in order to discuss the findings of the three empirical studies. The results are discussed against the original research aims, and methodological issues are reflected upon, before the implications for future research are considered.

Chapter 2: Type 1 diabetes - a psychosocial perspective

2.1 Introduction

Diabetes changes lives. For the child diagnosed with type 1 diabetes, they face a lifetime of diabetes management with the demands that impose on their physical and psychological well-being. For parents of a child with type 1 diabetes, they are expected to process the initial diagnosis whilst adapting to meet the needs of their child's diabetes health care and management until the child assumes responsibility in late adolescence. Therefore, this chapter will focus on the impact type 1 diabetes has on the lives of adolescents and parents, providing background information pertinent to the current research, and giving context to the overall aims of the thesis. The first part of the chapter will focus on the epidemiology and aetiology of type 1 diabetes, including a brief overview of the acute and chronic complications that may be experienced by individuals in later adulthood. This gives an insight into the biomedical characteristics of this chronic disease, highlighting the potentially devastating consequences if not managed optimally. The role of illness cognitions are then considered due to the importance and influence these may have on parental co-management of type 1 diabetes. Definitions of adolescence and the developmental processes that occur during this period are included to distinguish particular issues and parental concerns that relate to this patient age group. The next part of the chapter addresses parenting a child with type 1 diabetes and the psychological implications this can have. The chapter ends with the proposition that the Internet and online support groups could be a beneficial resource for parents of adolescents with type 1 diabetes. Structuring the chapter this way attempts to highlight the potential challenges faced by adolescents with type 1 diabetes as they adopt clinical autonomy for their diabetes management, but importantly the impact this has for parents, and the steps taken to deal with this - namely membership of diabetes online support groups.

2.2 Diabetes

2.2.1 Classification and epidemiology

Diabetes mellitus, more commonly known as diabetes, is a chronic disease estimated to affect over 9.3% of the world's adult population, and 1.1 million children and adolescents under the age of 20 years (International Diabetes Federation 2019). The number of people with diabetes has increased globally from 108 million in 1980 to 422 million in 2014, and 463 million in 2019 (WHO 2018, International Diabetes Federation 2019). By 2030, this number is forecast to rise to 578 million (Saeddi et al 2019). Without interventions to address this steady upward trajectory, it is predicted that by 2045 at least 629 million people worldwide will be living with the disease (International Diabetes Federation 2019). In the UK, the number of people diagnosed with diabetes has doubled since 1996 from 1.4 million to 3.8 million (Diabetes UK 2019). Factoring in undiagnosed cases, it is estimated that the actual number of people living with diabetes is 4.7 million, or approximately 6% of the population. Recent projections anticipate this figure is likely to rise to 5.5 million by 2030 (Diabetes UK 2019).

A disorder of the metabolic systems responsible for the storage and utilisation of glucose, diabetes occurs due to a lack of insulin or ineffective insulin action, as a result of the destruction of pancreatic beta cells, causing high blood glucose levels or hyperglycaemia (DeFronzo et al 2015). Classified according to aetiologies, the main types of diabetes are: i) type 1 diabetes, when the pancreas produces none to very little insulin; ii) type 2 diabetes, when insufficient insulin is produced and the body becomes less sensitive to the effects, termed insulin resistant; and iii) gestational diabetes, where insulin resistance is triggered by hormones produced by the placenta during pregnancy. In addition, some less common types include monogenic diabetes and secondary diabetes. Monogenic diabetes is caused by a specific single gene mutation. Examples include neonatal diabetes and maturity-onset diabetes of the young (MODY) (Hattersley and Patel 2017). Secondary diabetes occurs as a complication of other diseases e.g. cystic fibrosis, chronic pancreatitis or as a result of certain medications such as beta-blockers and corticosteroids (International Diabetes Federation 2019).

Type 1 and type 2 diabetes are the two main subtypes in the UK, with the latter accounting for approximately 90% of cases (NHS Digital 2018). Type 1 diabetes usually develops in childhood and adolescence whilst type 2 was historically rarely diagnosed before the age of 40. However, over the last 20 years there has been a considerable increase in the number of type 2 diabetes adult cases attributed to rapidly rising obesity levels, determined to be a significant risk factor (Hauner 2010). There has been a parallel rise in the incidence of childhood obesity in the UK. In 2000, the first cases of type 2 diabetes in children were reported in eight overweight girls aged 9 to 16 years (Ehtisham, Barrett and Shaw 2000). This number has increased year on year with the 2017-2018 National Paediatric Diabetes Audit (NPDA) reporting 745 children and adolescents, the majority of whom were obese, receiving treatment for type 2 diabetes in paediatric diabetes units (PDUs) in England and Wales. This may be a conservative estimate of the total figure, as it does not account for children treated in primary care (Royal College of Paediatrics and Child Health (RCPCH) 2019). Nevertheless, type 1 diabetes continues to be the predominant type of diabetes in children and adolescents in the UK.

Type 1 diabetes is one of the most common chronic diseases in childhood (Gale 2005). The incidence is increasing worldwide, particularly in children under the age of 15 years. In this global cohort, an estimated 600,900 children are affected by type 1 diabetes, with 98,200 new cases registered per year (IDF 2019). Recent estimates suggest over 32,000 children and adolescents under the age of 19 in the UK have diabetes (Diabetes UK 2019). The age of onset is variable, with the peak age occurring between the ages of 8 and 14 years in females but not until 2 years later in males (Pundziute-Lycka et al 2002). This has been attributed to earlier puberty in females with associated endocrine and metabolic changes affecting insulin resistance. Since the hormonal changes of puberty differ between the sexes, genes regulated by sex hormones could play an important role in the different patterns of disease presentation (Gillespie et al 2005).

2.2.2 Aetiology

The exact cause of type 1 diabetes remains largely unknown, but multiple contributing factors have been proposed. These include a genetic predisposition (Concannon, Rich and Nepom 2009, Pociot and Lernmark 2016) as well as environmental factors including dietary factors in infancy; the effects of breastfeeding, the determinants of early weaning, and the consumption of unmodified cow's milk (Rewers and Ludvigsson 2016, Sadauskaite-Kuehne et al 2004, Wijndaele et al 2009). The influence of viral infections in utero as well as rotavirus, rubella and particularly enterovirus in infancy and early childhood have also been considered as putative environmental factors with the potential to trigger the onset of type 1 diabetes (Hyöty 2016, Stene and Rewers 2012, Viskari et al 2012). Nevertheless, a direct causal relationship has not been proven (Rodriguez-Calvo and von Herrath 2015).

The notion of the 'hygiene hypothesis' as an epigenetic mechanism in the rise of type 1 diabetes in childhood has also been put forward for consideration (Jerram, Dang and Leslie 2017, Bach and Chatenoud 2012). Originating from research carried out by Strachan (1989) it proposes that the development of infections in early childhood decreases when there is non-hygienic contact with older siblings from the same family. Subsequent studies signal that the sibling effect in the first year has the potential to be protective against the development of type 1 diabetes, although the evidence is not strong (Cardwell et al 2008, Kaila and Taback 2001), and the 'hygiene hypothesis' *per se* has been criticised as overly simplistic and its explanatory scope too narrow (Bloomfield et al 2016).

Psychological stress and serious life events such as family conflict, bereavement, serious family illness or socio-economic problems have also been suggested as a potential environmental risk factor for type 1 diabetes during childhood (Sepa and Ludvigsson 2006). Sepa, Frodi and Ludvigsson (2005) analysed data from the *All Babies in Southeast Sweden* (ABIS) project; a longitudinal study of 16,070 children, to investigate if mothers' experiences of serious life events were associated with the development of diabetes-related autoantibodies in their children at age 2.5 years. The results showed mothers' experience of violence and divorce increased the risk of their child having developed autoimmunity at the age of 2.5 years threefold. Using a further subsample of 10,495 participants from the ABIS project, Nygren and colleagues (2015) prospectively investigated if serious life events, along with parental perceptions of parenting stress and lack of social support during their child’s first 14 years of life were a risk factor for manifest type 1 diabetes. While the authors reported no increased risk for parenting stress or social support, the risk of being diagnosed with type 1 diabetes before the age of 14 was three times higher if they had experienced a serious life event. These studies give further credence to the contribution of psychological stress to type 1 diabetes aetiology, with the association between serious life events and the induction of autoimmunity or manifest diabetes supported by the beta cell hypothesis (Ludvigsson 2006). This proposes that the experience of a serious life event could contribute to beta cell stress because of increased insulin demand or increased insulin resistance due to the physiological stress response; elevating cortisol levels which has an immediate effect on metabolism and the immune system (Carlsson et al 2014, Koch, Ludvigsson and Sepa 2010).

Etiologically a multifactorial disease, type 1 diabetes is characterised by the progressive destruction of beta cells of the pancreatic islets of Langerhans in the pancreas by the autoimmune system. This results in the total cessation of insulin production (Holt and Hanley 2012). A lack of insulin prevents glucose being used by muscle and adipose tissue, and glucose can no longer be stored in the liver, resulting in hyperglycaemia. The kidneys cannot recoup the excessive amount of glucose, which is then filtered out into the urine. This leads to loss of water as the glucose is secreted, and the fluid loss can be excessive (polyuria) leading to an increase in thirst (polydipsia). Insulin deficiency also leads to the breakdown of fats and the production of ketones, expelled from the body in the urine. Weight loss will occur due to the breakdown in adipose tissue, and if hypoglycaemia remains unchecked, the raised ketone levels can cause ketoacidosis. In this state, a person will experience symptoms that may include dehydration, vomiting and Kussmaul breathing, a form of hyperventilation. If ketoacidosis continues, the outcome will be diabetic coma, which if untreated can lead to death (MacArthur 2015).

The World Health Organisation (WHO) currently recommends four diagnostic tests for diabetes based on glucose measurements and the presence or absence of symptoms (WHO 2006, WHO 2011). Individuals with fasting plasma glucose values of ≥ 7.0 mmol/l (≥ 126 mg/dl), 2-hour postload glucose ≥ 11.1 mmol/l (≥200mg/dl), HbA1c ≥ 6.5% (48 mmol/mol) or random blood glucose ≥ 11.1 mmol/L (200 mg/ dl) in the presence of signs and symptoms meet the diagnostic criteria and are considered to have diabetes.

In children, diabetes usually presents with characteristic symptoms such as polyuria, weight loss and possible blurred vision in association with glycosuria and ketonuria. Sometimes ketoacidosis may develop, and this has been reported in about 30% of children at onset (Dabelea et al 2014). There may be an absence of symptoms or mild symptoms that are incorrectly attributed to an alternative condition, and diagnosis may require repeated monitoring and observation and periodic re-testing until it is confirmed.

2.2.3 Management and treatment

The management of type 1 diabetes in children is complex. Following diagnosis, the lack of naturally produced insulin means individuals are dependent on exogenous insulin (Atkinson 2012). Guidelines from the National Institute for Health and Care Excellence (NICE) on type 1 diabetes in children (NICE 2015) propose this is delivered either by multiple daily subcutaneous injections (MDI) or via an insulin pump as in continuous subcutaneous insulin infusion therapy (CSII). This mimics non-diabetic insulin secretion in response to food intake, activity levels and the underlying metabolic state. It is therefore necessary to measure carbohydrate intake at mealtimes in order to calculate the correct insulin dosage (NICE 2015). Understanding how to calculate this insulin-to-carbohydrate rate is vital as this varies for each individual. In addition, blood glucose levels need to be monitored on a regular basis to help detect hypo or hyperglycaemia. This is carried out either by a finger prick test, a flash glucose monitor or continuous glucose monitor (CGM). It is expected that four to six measurements a day will be taken, particularly before meals and at bedtime, but again this is dependent on the requirements of the individual (NICE 2015).

The National Institute for Health and Care Excellence (NICE) guidelines on type 1 diabetes in children and young people recommend that in addition to insulin therapy, diabetes management should involve ongoing education about diet, physical activity and lifestyle choices. All these aspects need to be carefully addressed and co-ordinated in order to achieve optimal glycaemic control and avoid acute complications such as hypoglycaemia and ketoacidosis and chronic complications including retinopathy, nephropathy, neuropathy and macrovascular complications (NICE 2015).

Whilst it is more usual for long-term complications to develop years or even decades after diagnosis, adolescents with poor metabolic control have been shown to have a higher risk of macrovascular complications as young adults (Anderzén et al 2016). Furthermore, a study by Lind et al (2014) examining the relationship between glycaemic control and mortality rates found the risk of death was several times higher among young people with poor metabolic control. It is therefore imperative that good metabolic control be achieved, with lower glycated haemoglobin A1c (HbA1c) levels associated with fewer or delayed complications (Nathan 2014). The recommended HbA1c target level from *The International Society for Pediatric and Adolescent Diabetes* (ISPAD) is below 7.5% (58 mmol/mol) (Rewers et al 2014). However, it has been shown that many adolescents managing type 1 diabetes still struggle to achieve these targets (Wood et al 2013, Miller et al 2015).

For children and adolescents, the goal of their co-managed diabetes care with parents or carers is to achieve a balance between reducing the risks of diabetic complications, with a good quality of life that ultimately affords normal growth and development. This requires ongoing and anticipatory care from a multidisciplinary clinical team of specialists to support the individual child and their family. It is recommended this should include a paediatric diabetologist, specialist diabetes nurse, dietician and psychological support from either a psychiatrist or psychologist (Pihoker et al 2018). However, it should be noted that children can develop type 1 diabetes at different developmental stages and may come from diverse ethnic, cultural and socioeconomic backgrounds. It is important that health professionals acknowledge this when considering how best to support children with diabetes and their families, by tailoring the management of diabetes on a case-by-case basis.

Whilst adults with type 1 diabetes are ultimately responsible for their own self-management, for children and adolescents, the onus is initially on parents (Sullivan-Bolyai et al 2003, Khandan et al 2018). Educating these primary caregivers about type 1 diabetes at diagnosis is paramount from health professionals and needs to be ongoing (NICE 2015, Phelan et al 2018). This acquired knowledge and understanding of the condition helps enable them to make more informed decisions about their child’s treatment and react accordingly (Lawton et al 2015, Ridge et al 2014).

2.2.4 Complications of diabetes

There are two major acute complications associated with type 1 diabetes, hypoglycaemia and ketoacidosis. Hypoglycaemia is the most common and occurs when blood glucose levels become dangerously low. Symptoms can include hunger, sweating, dizziness, palpitations as well as difficulty concentrating, weakness, drowsiness, blurred vision or difficulty in speaking (Cryer 1999). If the symptoms of hypoglycaemia are ignored and glucose levels not elevated, neuroglycopaenia may occur. Here the individual may show signs of lack of co-ordination and general confusion. Other behavioural changes shown to be particularly evident in children are agitation or irritability, quietness or stubbornness (Jones et al 1997). If glucose levels drop too low for a prolonged period, the individual can lose consciousness and if left untreated may die. Hypoglycaemia in adolescence is often attributed to poor glycaemic control, which in itself can cause further stress to both the individual and their family (Haugstvedt et al 2010).

Whilst there is no recognised or consistent numerical definition of hypoglycaemia for a child with diabetes, blood glucose levels between <3.3-3.9 mmol/L are the generally accepted values for identification. The *International Society for Pediatric and Adolescent Diabetes* (ISPAD) hypoglycaemia guidelines writing group proposed three levels for children and adolescents (Jones 2018). These include a glucose 'alert' value of ≤3.9 mmol/L (70 mg/dL) meaning attention is required to prevent hypoglycaemia, a glucose value of <3.0 mmol/L (54 mg/dL) which indicates clinically important or serious hypoglycaemia, and a clinically defined level of severe hypoglycaemia, associated with severe cognitive impairment (coma or convulsions). In this instance intervention from another person will be required to administer carbohydrates, glucagon, or respond with other corrective actions.

It is difficult to accurately quantify the incidences of hypoglycaemic episodes in children and adolescents due to the variations in the definition and the lack of reported episodes, especially in the case of mild hypoglycaemia (Ly et al 2014, Tasker et al 2007). Hypoglycaemia may also occur at night and on many occasions can be asymptomatic. A study by Wiltshire, Newton and McTavish (2006) addressing putative treatments to prevent hypoglycaemia at night used continuous glucose monitors with adolescents with type 1 diabetes. The authors found that most night-time hypoglycaemic episodes were mild and often went unrecognised. Hypoglycaemia or 'hypos' can be very traumatic for adolescents to experience and for some this can lead to developing a phobic-like fear of a hypoglycaemic episode. In order to overcome and minimize such episodes, individuals may deliberately keep their glucose levels slightly elevated (Leiter et al 2005). This fear has been shown to be an aspect of diabetes that continues to be psychologically traumatic and induces anxiety in adolescents and their parents even after a considerable time since diagnosis (Driscoll et al 2016).

Diabetic ketoacidosis (DKA) is a life-threatening condition, characterised by the triad of hyperglycaemia, acidosis and ketones in urine (Wolfsdorf et al 2018). If DKA is confirmed, immediate hospitalisation is necessary to replace lost fluids, and insulin therapy is needed to prevent further complications such as hypokalaemia (low levels of potassium) and cerebral oedema. In adolescents, episodes of hypoglycaemia and DKA have been explained by poorly self-managed treatment regimes. However, factors such as general health, the period of time since diagnosis, the individual’s perceived quality of life, ability to cope and family functioning have all been shown to have a bearing on the recurrence of DKA (Delamater et al 2018, Silverstein et al 2005).

Population studies have reported the mortality rate from DKA in children as 0.15%-0.30% (Maahs et al 2015), and may be declining (Decourcey et al 2013, Saydah et al 2012). Reasons for this remain speculative but may be due to improved diabetes treatment and care, increased awareness of symptoms, more intensive glucose monitoring that results in earlier treatment and advancements in education regarding diabetes and management (Brink 2014). Despite this, DKA remains the leading cause of death in children and adolescents with type 1 diabetes under the age of 15 (Morgan et al 2018).

Chronic hyperglycaemia is closely associated with microvasular and macrovascular changes (DCCT 1993). These chronic long-term complications of diabetes can develop many years post onset, with some patients' asymptomatic or displaying only subtle symptoms in the early stages (Marcovecchio and Chiarelli 2012). Microvascular complications affect the eyes (retinopathy) and kidneys (nephropathy). Findings from a large-scale study examining trends in diabetic retinopathy (DR) in the UK between 2004 and 2014, identified the prevalence of DR in patients with type 1 diabetes was 48.4% (Mathur et al 2017). Adolescents with poor glycaemic control have a greater risk of progressing to vision threatening stages of retinopathy than adults with diabetes, namely severe non-proliferate retinopathy or diabetic macular edema (Donaghue et al 2014). The importance of screening for early signs of retinopathy during adolescence should not be overlooked, as this may help identify modifiable risk factors that can have an impact on progression.

Diabetic nephropathy (DN) is a chronic complication where the kidney function deteriorates and if not addressed can lead to renal failure. There are five stages of deterioration, stage 1 being the mildest and stage 5 the most severe, called end-stage renal disease (ESRD). A progressive complication, previous studies have estimated a cumulative risk of 25-40% for diabetic nephropathy after at least twenty years post-diabetes onset (Ballard et al 1988). Kidney disease accounts for 21% of deaths in individuals with type 1 diabetes (Diabetes UK 2017). The *Diabetes Control and Complications Trial* (DCCT 1993) established poor glycaemic control as the dominant risk factor for the development of diabetic nephropathy. Whilst diabetes induced DN and kidney failure are uncommon in childhood and adolescence, this is a particularly vulnerable time when individuals may deviate from the prescribed treatment regime, thus accelerating the disease progression (Drummond and Mauer 2002, Svensson et al 2006).

Diabetic neuropathy is a common long-term complication of diabetes with significant morbidity and mortality in adulthood and is associated with a substantial reduction in quality of life (Ahola et al 2010). It is a type of nerve damage caused by long-term high glucose levels. There are three different types of neuropathy: sensory, motor and autonomic. Considered the most problematic with potentially life changing consequences, sensory neuropathy affects the nerves in the feet and legs. This can lead to problems such as neuropathic ulcers, a complication with the highest number of hospitalisations, or Charcot's foot, where bone and joint degeneration may lead to deformity or amputation (NICE 2015). Problems associated with all types of diabetic neuropathy increase with age and it is estimated that neuropathies may affect up to 50% of individuals with diabetes (Boulton 2005). Whilst clinical neuropathy is rarely seen in children, subclinical presentation is becoming more common, particularly in adolescents (Louraki et al 2012).

A major macrovascular complication of diabetes is atherosclerosis (Fowler 2008). This refers to the hardening and narrowing of the arteries caused by the slow build-up of plaque on the inside of walls of the arteries, which can lead to a restriction of blood flow. There are two types of plaque - hard and stable, soft and unstable. Hard plaque causes artery walls to thicken and harden, and soft plaque is more likely to break apart from the walls and enter the bloodstream. This can cause a blood clot that can partially or totally block the flow of blood in the artery. If this occurs the organ supplied by the blocked artery is starved of blood and oxygen, causing the organ's cells to possibly suffer severe damage or be completely destroyed. This can affect the heart, head and legs, and peripheral artery disease can lead to limb amputation. Type 1 diabetes increases the risk of cardiovascular disease by more than ten times, relative to the general population (Orchard et al 2006), with coronary artery disease identified as a leading cause of death in people with type 1 diabetes (Soedamah-Muthu et al 2006).

An increase in mortality and microvascular complications in early adulthood for those with type 1 diabetes is becoming more evident in the literature. The long-term prognosis for adolescents appears poor, with diabetes-related health problems contributing to an impaired quality of life and an increase in disability among an adult diabetic population (Cho et al 2015, Corriere, Rooparinesingh and Kalyani 2013). It is therefore important to consider the way adolescents with diabetes are managed initially and the diabetes education they receive including details about complications, in order to successfully co-manage their disease and delay the onset of complications in later life (Rewers et al 2014).

2.2.5 Cost of diabetes

The increasing incidence of diabetes also has financial implications for the National Health Service (NHS) in the UK. In the first evidence-based assessment of the long-term resource requirements for the NHS entitled '*Securing Our Future Health: Taking A Long-Term View*' (Wanless 2002) it was estimated that the total annual cost of diabetes to the NHS was £1.3 billion. This figure included the amount spent on avoidable diabetic complications, estimated to increase NHS costs more than five-fold. The report concluded that unless those with diabetes were engaged in all aspects of the proposed preventative programme, good health outcomes would not be achieved, and the NHS would be facing further financial burden. The financial cost has continued to increase year on year since the Wanless report and almost 20 years later conservative estimates propose the amount spent by the NHS on diabetes is at least £10 billion a year or 10 per cent of the NHS budget (Whicher, O'Neill and Holt 2020).

The monetary cost of research into the cause and complications of diabetes in the UK is an ongoing expenditure that has increased over the years following commitment from the UK Government in 2005 to invest £100 million in the UK Clinical Research Collaboration (DOH 2006). A National Institute for Health Research Diabetes Research Network (NIHR DRN) was established by the Department of Health in 2005 to provide a network of primary and secondary care centres conducting clinical research in the commercial and academic sectors. It works closely with other agencies such as Diabetes UK, the Medical Research Council, The Diabetes Research and Wellness Foundation (DRWF) all of whom invest varying amounts into diabetes research. Whilst it is impossible to accurately calculate the total UK expenditure on diabetes research in the private and public sector, it is important to note the acknowledgment from the Government of the importance of research which considers the short-term and long-term effects of diabetes on the health of the general population, and the repercussions this has for the NHS overall.

2.3 Understanding how people make sense of diabetes: the role of illness cognitions

Self-care behaviours play a major role in diabetes management and the degree to which individuals adhere to their diabetes treatment regime can be determined by their health beliefs and illness cognitions (Harvey and Lawson 2009). Models of health beliefs have been proposed which address the relationship between beliefs and behaviours including the Health Belief Model (Becker 1974), the Theory of Reasoned Action/Theory of Planned Behaviour (Ajzen and Madden 1986) and Protection Motivation Theory (Rogers 1983). Leventhal's Self-Regulatory Model takes into account both the emotional as well as objective response to illness and also the individual’s current and past experiences, making this the most suitable to consider for the current research.

2.3.1 Leventhal's Self-Regulatory Model

Leventhal and Nerenz defined illness cognitions as *'a patient’s own implicit common-sense beliefs about their illness'* (1985, p.517) and proposed these cognitions gave individuals a framework they could integrate with existing schemata for understanding and coping with their illness. Adopting an exploratory qualitative approach, Leventhal and colleagues carried out open-ended interviews with patients with a variety of different illnesses (Leventhal et al 1997, Leventhal, Meyer and Nerenz 1980, Leventhal and Nerenz 1985, Leventhal et al 2007). This methodology was chosen as Leventhal argued it would not only encourage individuals to share their own beliefs about their illness but would also avoid the possibility of priming participants. From the research, it has been established that individuals’ beliefs about their illness can be structured around five broad cognitive dimensions (Leventhal, Meyer and Nerenz 1980):

1. *Identity* - the label given to the condition and associated symptoms.
2. *Cause* - the causes may be biological, for example a virus, or psychosocial such as stress. Individuals may have representations of illness that have been shaped by personal experience and the interactions they have had with significant others.
3. *Timeline* - the individual's belief about the duration of their illness, and differentiates between acute and chronic. This is re-evaluated over time.
4. *Consequences* - the individual's belief about the effects of the illness on their life both physically and socially. Representations held are liable to change and become realistic over time.
5. *Cure and controllability* - the belief the individual has as to what degree the illness is curable or can be controlled.

Leventhal incorporated these illness cognitions into his self-regulatory model (often referred to as common sense model) (Leventhal et al 1985). This suggests that individuals deal with their illness and symptoms in a similar way as with other problems, whereby when they encounter a problem (in this case illness), the individual will be motivated to solve the problem to regain normality. The problem solving takes place in three stages, as represented in Figure 1.

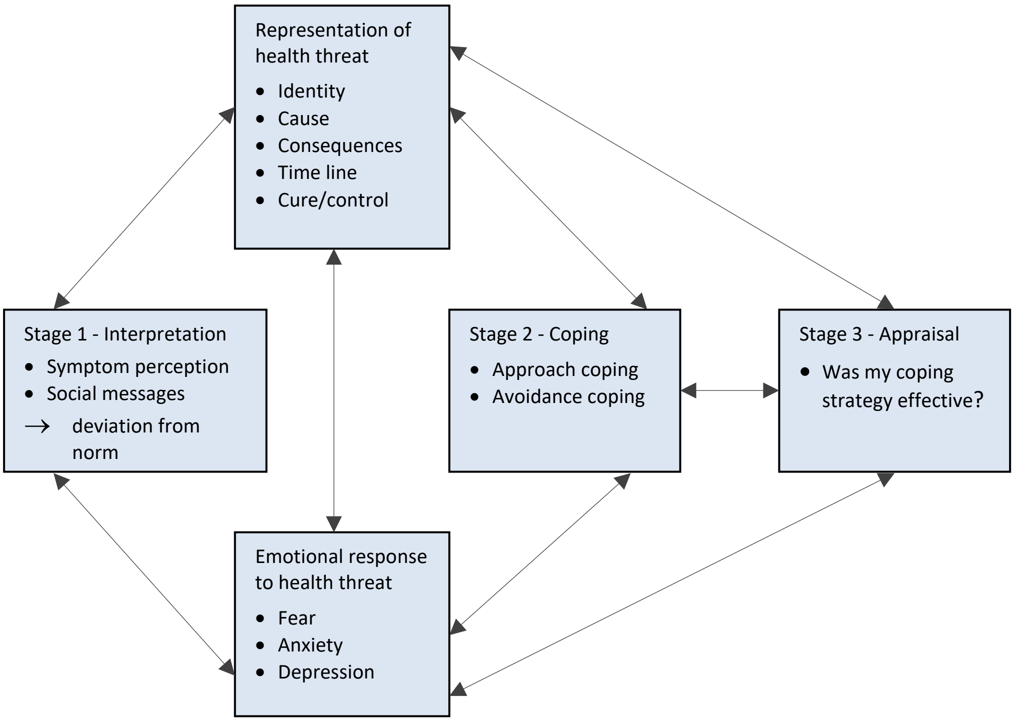

Figure 1 - Leventhal's self-regulatory model of illness behaviour (Ogden 2012)

Briefly, the three stages are:

Stage 1 - *Interpretation*

This is the stage when an individual is first confronted with the dilemma of trying to identify symptoms either through symptom perceptions such as 'I have a headache', 'I feel nauseous', or social messages, 'the doctor has diagnosed glandular fever.’ When they have obtained information about the possibility of illness via either (or both) of these channels, the course of action according to Leventhal is a desire to return to pre-symptomatic normality. Meaning is given to the identified problem and this is determined by the illness cognition the individual holds. Dynamically, the symptoms and social messages will directly add to and shape the illness cognitions, and these are constructed along the dimensions of identity, cause, consequences, timeline and cure/control. The meaning assigned to these representations will help the individual develop strategies to cope with the problem.

Stage 2 - *Coping*

The second stage in the Leventhal model is the development of various coping strategies, dictated by the illness cognitions. These strategies can vary according to the individual, and two broad categories have been identified that incorporate many of the characteristics of others, namely 'approach coping' where the individual follows a pro-active path, e.g. visits the doctor, and takes the prescribed medication, and 'avoidance coping' where the individual may deny the problem exists or refuses to see a doctor.

Stage 3 - *Appraisal*

The third stage is appraisal. This is when individuals consider the efficacy of the coping strategy they have used and on the basis of this decide whether or not to continue with or adopt another strategy.

These three stages are interrelated in order to regulate the self. As a result, when an individual feels their normal state of health has been unbalanced by illness, they will undertake actions to try to restore the balance of health back to a more normal *status quo*. In this way, self-regulation is dynamic and consequently interactions can take place between the stages.

While Leventhal and colleagues used qualitative semi-structured in-depth interviews to identify patients' illness representations in their original work, this approach can be potentially time-consuming and costly, producing large variations in the responses from participants, in terms of both quantity and quality. Weinman et al (1996) developed the theoretically based and psychometrically sound Illness Perception Questionnaire (IPQ) to provide a quantitative assessment of the illness representations described in Leventhal's self-regulation model (Leventhal et al 1984). A revised version of the IPQ, the Revised Illness Perception Questionnaire (IPQ-R), was published in 2002 with improved psychometric properties and 3 additional subscales: cyclical timeline perceptions, illness coherence and emotional representations (Moss-Morris et al 2002). Disease-specific versions of the IPQ-R have subsequently been developed and include questionnaires for HIV, asthma, hypertension, autism, rheumatoid arthritis and diabetes. The authors also propose that the scale can and should be modified for use in different contexts (Moss-Morris et al 2002). It has become a widely used instrument for the assessment of illness perceptions in areas such as coping, treatment adherence and health outcomes.

Leventhal's Self-Regulatory Model (Leventhal et al 1984) provides a conjectural framework for research that has employed the IPQ and IPQ-R (Moss-Morris et al 2002, Weinman et al 1996) to investigate the illness representations of adolescents with chronic conditions, as well as parents emotional and behavioural responses to their child’s chronic illness based on individuals’ cognitive representations of the disease.

A systematic review carried out by Law, Tolgyesi and Howard (2014) addressed the extent to which illness representations relate to self-management in children and adolescents with a chronic health condition. Of the fifteen studies considered in their review, 10 investigated the role of illness representations in diabetes self-management. There was variability between the results in the diabetes studies reviewed, but there was some evidence to indicate that certain dimensions of illness representations were more strongly associated with diabetes self-management than others. The literature identified that treatment control beliefs were significantly associated with diabetes self-management relating to dietary self-management (Nouwen et al 2009, Skinner and Hampson 1998, Skinner, John and Hampson 2000, Skinner et al 2003), blood glucose monitoring (Gaston, Cottrell and Fullen 2012, Skinner and Hampson 1998, Skinner et al 2003), and exercise (Skinner et al 2003). These results would suggest that adolescents who believe their diabetes is controllable by the prescribed treatment are more likely to follow and engage in self-management behaviours. Furthermore, it is possible to distinguish a difference between the short-term control beliefs (i.e. effectiveness of treatment to control diabetes on day-to-day basis) and long-term beliefs (i.e. treatment to prevent complications). This was demonstrated in the study by Gaston, Cottrell and Fullen (2012) where adolescents who had greater belief that their diabetes treatment would be effective in preventing future health complications reported better blood glucose monitoring. This finding also relates to the perceived consequences domain of illness representations and can have an impact on outcome expectancies. Iannotti et al (2006) found self-efficacy had a greater association with diabetes self-management when positive outcome expectations were high and low consequences relating to diabetes were perceived.

Law, Tolgyesi and Howard (2014) argue not all illness representations have a role to play in self-management behaviours. They further speculate that not all illness representations are equal, and that they and the self-regulatory system that underpins Leventhal's model do not occur in isolation (Diefenbach and Leventhal 1996). The authors suggest the illness representations of adolescents should be considered beyond the individual level, taking into account and acknowledging the influence parents can have on both their child’s illness representations and health-related behaviour.

Studies have explored the illness representations of adolescents with a chronic condition along with those of their parents. Olsen, Berg and Wiebe (2008) explored dyadic dissimilarity in illness representations and emotional adjustment between 84 mothers and their adolescent child with diabetes. Both groups completed the IPQ-R (Moss-Morris et al 2002), with the adolescents negative emotional adjustment measured using three scales: The Children’s Depression Inventory (CDI) (Kovacs 1985), Positive and Negative Affect Schedule (PANAS) (Watson, Clark and Tellegen 1988) and The Diabetes Quality of Life (DQOL) scale for youth (Ingersoll and Marrero 1991). The PANAS (Watson, Clark and Tellegen 1988) and the Centre of Epidemiological Studies of Depression Scale (CES-D) (Radloff 1977) was used to measure maternal negative emotional adjustment. The results showed differences between the two participant groups in how they each represented the adolescent's diabetes. Mothers viewed diabetes as being more chronic and associated with more negative emotional consequences. In contrast to adolescents, mothers believed they had more control over the disease than their child perceived they had. These differences are of importance, as such disparity may lead to conflict and a disruption of cohesion within the family unit (Miller and Drotar 2003, Skinner, John and Hampson 2000). This can have potentially deleterious consequences for the adolescent in terms of reduced well-being and an increase in illness-related strain (Field and Duchoslav 2009). As a consequence, this may affect parents' levels of emotional distress when co-managing an adolescent with a potentially life-threatening chronic condition such as diabetes (Hilliard et al 2013, Popp et al 2014).

The development of an individual’s illness representations, be they adolescent patient or parent thereof, is considered to be informed and modified by three main sources of information: their current experience of the illness, lay knowledge about the illness, and knowledge obtained from external sources such as information given by health professionals (Leventhal, Meyer and Nerenz, 1980, Leventhal et al 1984). These representations can influence how an individual responds to and manages the illness that affects them, either directly or indirectly (Weinman and Petrie 1997).

2.4 Adolescence and diabetes

2.4.1 Adolescence - a definition and perspective

Adolescence is a relatively modern concept identified as occurring between the ages of 12-19 years (Silverstein et al 2005) and as a *'transitional developmental period between childhood and adulthood characterised by more biological, psychological and role changes than any other stage of life except infancy.’* (Feldman and Elliott 1990, p.410). Hall (1904) is credited with giving adolescence its first full definition and suggested the experience of adolescence was primarily underpinned by biology linked closely to the concept of evolution drawn from Darwin's earlier work in this area. Hall hypothesised that adolescence is a period of disturbance of the child's self-image*, 'the age of storm and stress'* (Hall 1904, p.xiii). This refers to the decreased self-control seen in adolescents (the '*storm*' part of the hypothesis) versus the increased sensitivity in adolescents to various arousing stimuli around them (the '*stress*'). Physiological changes affected psychological equilibrium and Hall identified this as affecting adolescent behaviour in the following ways - conflict with parents, mood disruption and engaging in risky behaviours.

Whilst Hall's '*storm and stress*' hypothesis remains an influential developmental framework of historical significance that paved the way for future child and adolescent development theorists such as Piaget (1970), Erikson (1959) and Marcia (1980), more contemporary perspectives contend that whilst adolescence may be stormy and stressful for some it is not inevitable or ubiquitous (Steinberg 2001).

Hollenstein and Lougheed (2013) reconsidered the '*storm and stress*' hypothesis and rather than questioning whether storm and stress occurs in all adolescents, they considered when changes occur and how they present. Synthesising a large body of research and taking into account a number of adolescent emotional development models, the authors developed the 4T approach, supported by the following six premises about adolescent emotional development:

1. The biological changes of adolescence are inevitable and ubiquitous - in the majority of circumstances except in rare medical conditions, all adolescents will experience the same physiological changes. This includes significant changes in hormone levels, with testosterone and estradiol rising to adult levels in late adolescence (Susman and Rogol 2004).

2. Adolescent biological changes drive various mechanisms of adolescent behaviour - changes in hormone levels have been shown to

directly and indirectly affect adolescent behaviour. The effect of testosterone on aggressive behaviour appears to be strongest under conditions of perceived social threat (Rowe et al 2004), but it has been noted there is a hormone/environment interaction that accounts for individual differences in behaviours (Powers 2011). As well as hormonal changes, neurological changes occur which affect the limbic system and prefrontal cortex in the brain, responsible for emotional functioning, and this goes some way to explaining greater instances of impulsivity and sensitivity that underlie conflict, mood and risk taking (Dahl 2001).

3. Adolescent biological changes are shaped by environmental influences - biology and environment both have an influence in how an adolescent develops socially. Certain genes may be affected by environmental factors. For example, the 5HT transporter gene responsible for regulating serotonin levels can be altered by specific environmental experiences, such as stress or emotional abuse (Caspi et al 2005), substance or alcohol abuse (Nilsson et al 2005). A further example of environmental influence on biological processes during adolescence is the effect of family conditions on the timing of pubertal development in girls. Belsky et al (2007) found that the absence of a biological father during a girl's childhood and less supportive, harsher family interactions resulted in puberty and the onset of menarche at an earlier age. Neuronal changes also take place due to exogenous input, whereby environmental factors affect biological processes, which then drive behaviour. Synaptic pruning can be used to explain this; where experience shapes neural pathways that changes the neurological brain structure.

4. Individual differences in adolescent emotional behaviour changes are domain specific and vary in intensity - each emotionally challenging event for an adolescent involves a coping strategy, which may either have a successful of unsuccessful outcome. An adolescent faced with peer rejection may become withdrawn or aggressive or conversely may

become more outgoing with other peers or family members. How adolescents respond to challenging events is dependent on individual differences and this means makes predicting behaviour when faced with a new challenge difficult.

5. There are individual differences in the age of onset and duration of adolescent change - biologically there is a wide difference in developmental timing across individuals, with 90-95% of girls having their first menses between the age of 11 and 15 (Anderson et al 2003). Body development in the same age group can also vary by as much as five years and maturational discrepancies have been linked to anxiety, depression and delinquency (Ge and Natsuaki 2009). Individuals who physically mature at an earlier age may face increased pressure to engage in more adult orientated activities and there is a discrepancy between physical and emotional maturity that needs to be acknowledged.

6. Individual differences in the duration and intensity of transitions in emotional arousal are functionally modulated by emotion regulation skills - we are all born with biological mechanisms of emotional arousal but learn through experience to regulate these. For adolescents who become aware of their changing body there can be a significant disparity between their capacity for emotional arousal and their ability to regulate it, and the timespan and degree of this disparity varies according to the individual.

Hollenstein and Lougheed (2013) contend that Hall's (1904) '*storm and stress*' hypothesis is too simplistic, out-dated and offers a limited and pathologized view of the multifaceted organic processes that take place during adolescence. As a contemporary alternative, their 4T approach necessitates the integration of the following: typicality, temperament, transitions and timing:

1. Typicality - this means the normative processes of moving out of childhood and through adolescence. Much of the previous research has

focused too heavily on problem behaviours and overlooked what could be viewed as the natural development during adolescence. More research is needed to address this discrepancy.

2. Temperament - the notion that temperament refers to a developmentally fixed innate set of emotional responses has been challenged (Laceulle et al 2012), and can be considered as a way to summarise emotional responses at different points in life, which can change due to developmental maturation and environmental influences. Whilst the research in this area is scant, it is worth noting the extra dimension a temperamental focus could add to models of adolescent development.

3. Transactions - there are constant transactions between the body's biology and the external environment, and these are reflected in changes to the central and autonomic nervous system, the HPA axis and the endocrine systems. Whilst the idea of the development of an individual as a dynamic system has been accepted (Hollenstein 2011), a more specific application of a dynamic systems approach tailored for adolescent typical phenomena is preferred (Kunnen 2012). This will take into account adolescents may be less experienced in dealing with stressful situations and their responses.

4. Timing - this is an often overlooked aspect of adolescent development (Granic 2005) and refers to the age of onset of certain physiological changes such as puberty or changes in behaviour. Not every adolescent develops at the same rate, therefore chronological age is not necessarily a good measure of an adolescent's functional maturity regardless of the arbitrary age requirements set by certain agencies i.e. the legal age to drink alcohol, vote, drive a car or marry.

What Hollenstein and Lougheed (2013) offer with their 4T approach is a novel systems-based framework with which to consider contemporary adolescent development. The authors have taken into account the biology of the individual, the environment they inhabit, the reciprocal interaction between these and the outcomes. They conclude that development is systemic, both atomistic and interpersonal, and that the complexities of adolescence require such an approach. When considering the development of adolescents with type 1 diabetes, this framework offers a pertinent approach as it can situate the person within their environment whilst taking into account the physical and emotional effect diabetes may have and the consequences of this.

2.4.2 Adolescence and diabetes

As noted by Hollenstein and Lougheed (2013) the transition from childhood to adulthood is complex and involves an interplay between the physiological, social and psychological. Managing this with a chronic condition such as diabetes is an added complication that may be physically and emotionally debilitating for the individual. A well-documented behaviour during adolescence is risk-taking (Steinberg 2004). Defined as the participation in activities or behaviours that can compromise the mental and physical health of the individual, adolescents may begin to experiment with behaviours including smoking, drinking, drug use, violence and unsafe sexual activity (Reyna and Farley 2006).

It has been hypothesised that a chronic condition such as diabetes acts as a protective factor against engaging in risky behaviours during adolescence (Frey 1997). Nevertheless, there is a growing body of literature indicating that adolescents with chronic conditions are as likely (and in certain instances more likely) to adopt risky behaviours. In comparison to their healthy peers, these behaviours may have more harmful consequences due to the short and long-term health complications of diabetes (Suris et al 2008). A study by Scaramuzza et al (2010) set out to assess whether adolescents with type 1 diabetes differed from their healthy peers with regard to risky behaviour. 215 participants aged 12-18 recruited from five diabetes summer camps completed a questionnaire derived from the Youth Risk Behavior Survey (Brener 1995) with 140 structured questions to determine the prevalence of alcohol and tobacco consumption, illicit drug use and sexual behaviour. They also evaluated the frequency of mismanagement related to diabetes care by assessing metabolic control by self-report and by measuring the most recent HbA1c obtained during the previous 1-3 months, and suicidal intention was also investigated. A control group was recruited among high school students with similar demographic characteristics in terms of age, sex and family composition.

The overall results showed that the participants with diabetes were as likely as the control group to engage in risky behaviour and in some instances more so. The male diabetic group showed a significantly higher rate of tobacco use than the control group, but there was no significant difference for alcohol, cannabis or other illicit drugs. The female diabetic group showed higher rates for illicit drugs and alcohol consumption than the control group. With regards to sexual behaviour, the diabetic group had a similar rate of sexual intercourse among the males and lower rates among females. In the diabetic group those who engaged in risky behaviour showed higher rates of treatment mismanagement, including missing insulin shots, missing meals and reporting false blood sugar readings. The HbA1c was higher in those participants who engaged in one or more risky behaviours in comparison to those who did not, and this highlights the fact that even though the participants were aware they were engaging in risky behaviour and were aware of the consequences they still chose to do so.

2.4.3 Managing adolescent diabetes

It has been recognised that the care and management of diabetes in adolescence is changing and needs to be handled in a different manner to treating diabetes in adults (Rea 2014). This reflects the increasing numbers of paediatric and adolescent cases and a growing awareness by health professionals of the heavy demands diabetes places on individuals within this age group. The complex physical, developmental and emotional needs during adolescence require specialised structured education to ensure the best long-term management of diabetes delivered by health care professionals with appropriate training in the principles and practices of education (Knowles et al 2006). The Paediatric and Adolescent Diabetes Group of the Royal College of Nursing (2006, p.2) have made explicit their views about what the overall goal of managing diabetes should be:

> *'to enable the child or young person to lead a life as free as possible from the clinical and psychosocial complications of the disease. This requires that blood glucose is well controlled.... and that adverse lifestyle factors are modified to prevent long-term complications. Most importantly, children and young people must be involved in making decisions about their management.... and should be offered an on-going integrated package of care by a multidisciplinary paediatric diabetes care team with the required competencies.'*

Being involved in decisions about their diabetes management is intrinsically tied in with diabetes education and how this is executed. Chaney et al (2012) in an exploratory qualitative study ran focus group interviews with 21 adolescents aged 13-19 to determine their beliefs regarding the need for structured diabetes education and how this could be actioned as well as the topics to be addressed. The authors reported that many of the adolescents struggled with the demands of the current regime and did not feel confident about getting advice from health care professionals or their parents. They said they would be prepared to attend a structured diabetes education programme that ran as one session a week for four weeks, and emphasised the things they could do rather than the things they could not. Many felt parents and health professionals emphasised the negative aspects of diabetes and the adolescents wanted a more positive message to come from an education programme. Parental involvement was also discouraged by the majority of the participants, who felt this hampered their independence. They did acknowledge the need to provide information about the programme for their parents but felt this could be done via a leaflet. Similarly, a more detached follow up by text message was the preferred option for future communication.

A growing body of research continues to support the Chaney et al (2012) findings and this advocates the importance of involving adolescents in the design, ethos and implementation of education programmes. In recent years several UK Government commissioned guidelines and recommendations have been produced which have addressed this issue. The *National Service Framework (NSF) for Diabetes* first published in 2001 contains several standards applicable to children, along with *The National Service Framework* (NSF) for *Children, Young People and Maternity Services* (2004) whose main themes advocate high quality integrated health and social care. In 2015, the National Institute for Clinical Excellence (NICE) published a quality standard covering the diagnosis and management of diabetes in children and young people. All of these guidelines stress the importance of appropriate ongoing diabetes/health education, and educating adolescents about the complications of diabetes has been shown to be predictive of better self-care and control (Swift 2009) but requires sensitivity and tailored supervision. The educational techniques previously used with children and adolescents have changed from didactic presentations to interactive interventions, where the strength lies much more with the notion of positive empowerment of patients. However, it can be challenging for healthcare providers to develop strategies for adolescents, as these should acknowledge that adolescence is a distinct developmental stage, differentiated from childhood or adulthood by particular characteristics, both physiological and psychological. It has been proposed that more practical models of diabetes education and management which emphasise the uniqueness of each adolescent with regards to personality, family and peer influence should be utilised and this includes using current technology where and when applicable (Wiley et al 2014).

A paper by Duncan and Young (2013) identified a number of key themes about providing health care services for adolescents in the field of genetics, which may be applied to adolescent diabetes. These included health professionals acknowledging and supporting adolescents emerging autonomy within a health-related framework and noting the need to consolidate ideas about adolescent friendly healthcare practice. They also identified potential barriers when dealing with adolescents that have previously not been fully explored. These included health professionals’ concerns and preconceived ideas about adolescent cognitive capacity and competence, as well as the education, training and competence of health professionals themselves.

For an adolescent with diabetes, the pressure to manage their condition places responsibilities upon them they may not wish to, or are unable to shoulder, and this can lead to a reduction in metabolic control. Research over the last 25 years highlights those individuals supported socially and psychologically as more adept at coping with their diabetes. Consequently, they are more inclined to be treatment compliant, encouraging greater glycaemic control (Gage et al 2004, Hilliard et al 2016, La Greca et al 1995, Skinner and Hampson 2000, Wiebe et al 2016, Weissberg-Benchell, Wolpert and Anderson 2007).

The '*health-equilibrium*' that individuals with type 1 diabetes strive for is ultimately related to the compliance criteria defined by health professionals (Sartorius 2006). A large number of health professionals may play a part in an individual's treatment, and there may be transient and brief encounters with clinicians or long-term relationships that endure during the course of childhood and adolescence. The importance of these relationships for adolescents with diabetes should not be overlooked, nor reduced to merely a '*doctor/patient*' relationship, as they are complex and influential (Rose et al 2002). Pro-active management involving the individual with diabetes and significant others including health professionals, family members and friends, is positively advocated by the current NHS policies regarding diabetes services for children and young people (NHS 2016). However, this coalition does not always run smoothly and there is significant evidence to show that conflict exists between adolescents, parents and healthcare professionals regarding diabetes specific supervision and responsibility for managing diabetes management tasks (Helgeson et al 2008, Hilliard et al 2013, Viikinsalo et al 2005). This conflict has frequently been cited as being associated with decreased glycaemic control, which in turn places a strain on relationships, leads to anxiety and can affect the overall quality of life of the individual during a time of physical, psychological and social development (Hilliard et al 2011, Lewin et al 2006, Rybak et al 2016, Wiebe et al 2014).

2.4.4 Coping with diabetes in adolescence

Progressing through adolescence can be a difficult time. For adolescents with diabetes there are additional stressors in comparison to their non-diabetic peers, which at times may appear latent, but are for them a constant reminder of the disease. Immelt (2006) has suggested that adolescents negotiating life with a chronic disease face a higher risk of behavioural and emotional problems in comparison to their healthy peers. Type 1 diabetes necessitates individuals managing and coping with a complex regime that involves monitoring blood glucose levels, carefully considering diet and exercise options, and daily insulin injections. At a developmental stage in life when adolescents desire conformity and sameness with their peers, diabetes can have the effect of setting them apart and emphasising a physical vulnerability or imperfection (Holmbeck et al 2002).

The imposition and restrictions on independence and individualism because of diabetes may be more manageable if the individual is able to exercise some form of coping strategy; shown to be crucial for emotional and social development among adolescents in general (Zimmer-Gembeck and Skinner 2008). Schmidt, Peterson and Bullinger (2003) highlighted the developmental aspects related to coping with a chronic disease. They noted coping and development seem inherently interconnected with age-related factors playing a major role in shaping adaptational processes to stress (La Greca et al 1992). For children diagnosed with type 1 diabetes, increased levels of coping skills learnt and developing from early childhood may continue to be of benefit as they negotiate the normative developmental transitions to adolescence. At this stage, they will need to adjust to and manage accordingly, different symptoms of diabetes in order to reduce the risk of developing long-term secondary complications, both physical and psychological in later adult life (Anderzén et al 2016). Other researchers have hypothesised that coping strategies differentiate into several dimensions in adolescence (Kavsek and Seiffge-Krenke 1996), with cognitive and emotional coping strategies developing with age and related to the challenges that adolescents with a chronic disease may face. This includes puberty, changing schools, negotiating their changing role within the family and developing relationships with peers (Holmbeck at al 2006), all considered stressful. The adaptational processes that develop may do so as a response to this stress.

Stressful life events have been shown to increase during adolescence and linked with an increase in anxiety, self-esteem issues and depression (Byrne et al 2007). For adolescents with diabetes, stress is an important area to consider, with high levels correlated with the deterioration of metabolic control (Delamater et al 2013). Understanding and attempting to improve illness coping and self-care for adolescents with a chronic condition has been viewed as important by researchers to try to stem long-term health and psychological problems (Jaser et al 2016).

2.5 Transition from paediatric diabetes services

In the UK, the transfer of responsibility for diabetes self-management by the adolescent becomes more apparent when they move from NHS paediatric diabetes services to adult services either directly or via transition clinics during late adolescence. This transition has been defined as *'the period of time during which there is planned, purposeful and supported change in a young adult's diabetes management from child orientated to adult services, mirroring increasing independence and responsibility in other aspects of their life'* (Association of British Clinical Diabetologists 2012, p.6).

Whilst there continues to be professional consensus and updated government policy postulating how best to achieve a smooth transition of care in the UK (NHS 2016), variations in delivery exist with no standardised approach adopted. There is no set age criterion for transition, however the period of late adolescence, typically 16-19 years of age, is when most individuals will move from paediatric to adult health services. Comprehensive recommendations put forward from the Diabetes Transition Service Specification document (NHS 2016) address how best to implement a smooth and satisfactory move from paediatric to adult diabetes services. These support the notion that transition should be decided on an individual basis, after consultation with the patient, their family and on the advice of their health care team. The age of transition should depend on the physical development and emotional maturity of the individual rather than hospital policy. Coordinated transition in diabetes healthcare is necessary in order to assist the individual to self-manage their diabetes successfully, reduce the risk of long-term complications and encourage self-efficacy at a stage when they more susceptible to deterioration in their glycaemic control due to physiological and/or psychological changes.

It has been acknowledged that the transition from paediatric to adult health services needs to be situated in the context of the wider psychosocial changes the individual and their family are experiencing. For the previously dependent child, becoming an independent young adult required to manage their own diabetes care may have negative consequences (Helgeson 2009, Sheehan, While and Coyne 2015). A change in health care provision and self-care health responsibilities may also occur at a time when other significant events are taking place, for example, leaving school, starting college/university, or leaving home (Hanna 2012). This may be challenging and could lead to disengagement with adult health services, sub-optimal self-management, and poor glycaemic control resulting in more hospitalisations (Downing et al 2013). Social support from family, friends and health professionals during this period of change has been shown to be paramount in negotiating the process of a successful transition whilst coping with the additional responsibility and autonomy (Allen et al 2011, Monaghan, Helgeson, and Wiebe 2015, Weissberg-Benchall, Wolpert and Anderson 2007).

2.6 Family support

Involving the family in an individual's disease management as an aid to optimising adherence to treatment has been supported by researchers and health professionals (La Greca 1995 et al, King et al 2014, Wysocki and Greco 2006). Regardless of family composition, positive family attributes such as support, warmth, cohesion and an overall supportive family environment with low conflict have been shown to be associated with better diabetes self-care behaviours and metabolic control in adolescents (Drew et al 2010, Geffken et al 2008, Iskander et al 2015, Palmer et al 2011). Smith and Shuchman (2005) noted that family support was a crucial factor in the compliance of chronically ill adolescents, and parental support independently predicts good compliance with health regimens among adolescents with chronic illness.

A body of research investigating conflict between parents and adolescents with diabetes has found it to be associated with poorer glycaemic control (Anderson et al 2009, Hilliard et al 2013, Main et al 2015). However, Viikinsalo et al. (2005) reported that having diabetes did not increase conflicts with parents. In this study with 161 adolescents with type 1 diabetes and their parents, general day-to-day conflict issues were ranked and compared against those identified by a comparable cohort without diabetes (Riesch et al 2000). The authors put forward the notion that family relational bonds are inclined to be more stable and durable than others, and arguably less likely to change because of disputes. Results from the study found adolescents with type 1 diabetes and their parents reported experiencing conflicts about day-to-day issues similar to those reported by adolescents without diabetes. Furthermore, less general mother-adolescent conflict was perceived by the adolescents with diabetes, leading the authors to conclude that type 1 diabetes does not appear to heighten normal developmental conflicts within the family. Conflicts where the parent and adolescent were able to maintain positive ties could have a positive effect on the adolescents' life adaptation skills. Even if an adolescent has a chronic illness, effective parenting skills are still needed to assist the individual in creating an entire repertoire of life skills, coping strategies, and emotional resilience that a non-diabetic adolescent would require for their personal social development. This shows the importance of a supportive rather than controlling relationship, and this allows the adolescent to develop in a way more in keeping with their non-diabetic peers (Young et al 2014).

Supportive constructive parental relationships have resulted in adolescents reporting higher levels of self-care, increased psychological well-being and improved glycaemic control. In 2008, Cameron et al undertook a large-scale study with 2062 adolescents and 1994 parents from 21 paediatric diabetes care centres in 19 countries to assess the importance of family factors in determining metabolic outcomes in adolescents with type 1 diabetes. A variety of questionnaires were completed by the participants, including the Parental Involvement Scale from the Diabetes Quality of Life for Youth-Short Form (DQOLY-SF) and the Diabetes Family Responsibility Questionnaire (DFRQ). Parents completed the DFRQ and a Parental Burden of Diabetes score. Consistent with previous research the results showed that aspects of family structure, family dynamics and communication were robust determinants of glycaemic control during adolescence. Support from the family was viewed as being related to the levels of responsibility adolescents felt they had in managing their diabetes, the perceived levels of involvement from their parents and the parent–adolescent concordance on responsibility for diabetes care. It has been hypothesised that during adolescence, psychological and self-management interventions that include a focus on family relationships and communication may be more effective than interventions that focus on the individual adolescent, and the findings from the Cameron et al (2008) study would support this.

The role of communication and the importance this has in enabling family support for adolescents with diabetes was examined by Ivey, Wright and Dashiff (2009) as a sub study of a larger longitudinal study of adolescents with diabetes. A secondary qualitative analysis of data was carried out on taped interviews from 28 adolescents with diabetes and their parents. Five recurrent themes were identified - fear, frustration, trusting, normalizing and discounting. 'Fear' was defined as dread of an unpleasant or regrettable outcome, with 'frustration' relating to issues around the adolescent’s assumption of responsibility for their diabetes care. 'Trust' related to both parties being able to count on each other to meet certain behavioral expectations for diabetes management behaviors. 'Normalizing' dealt with how the family tried to view diabetes as a normal part of life, with 'discounting' representing a failure to include the adolescent in discussions about the issues related to diabetes management, and a lack of respect for their opinions or efforts. From both the adolescent and parental perspective, managing issues related to diabetes identified within these themes required negotiation that could at times be problematic for either party, but it appeared that co-directional support existed within the family.

The study by Ivey and colleagues (2009) lends further credence to the notion that support from family members may be beneficial in alleviating feelings of fear and frustration for adolescents who feel alienated from others because of their diabetes. However, whilst the literature expounds on the physical benefits of family support for the adolescent, i.e. improved glycaemic control, it may be challenging to find a suitable level of parental involvement and support that satisfies both the parent and the adolescents’ requirement at the same time. Adolescents may look to significant others such as peers and friends to provide an additional different type of support (Peters, Nawijn and van Kesteren 2014, Raymaekers et al 2017).

2.7 Parenting a child with diabetes

Parents with a child diagnosed with diabetes may initially go through a variety of emotions, including uncertainty, fear, anger, loss, and guilt (Rankin et al 2014). They may experience a grief reaction more often associated with bereavement (Bowes et al 2009). It has been hypothesised that the grieving process is a linear one that results in resolution or acceptance (Worden 1995). For those parenting a child with diabetes, this grief reaction may be subdued over time but can resurface when triggered by circumstances or at critical times during their child's development. This is indicative of the concept of chronic sorrow proposed by Olshansky (1962) where parents of children with chronic conditions do not manage to reach the resolution or true acceptance stage. Whilst parents may attempt to adjust and adapt to the situation both in a practical sense and as a psychosocial transition it does not signify acceptance (Lowes, Gregory and Lyne 2005).

2.7.1 Parental stress and depression

Bowes et al (2009) carried out a study with parents of children with type 1 diabetes 7-10 years after diagnosis exploring their longer-term experiences. In-depth interviews with 17 parents from a convenience sample recruited in Wales provided findings that where congruent with Olshansky's original concept. The grief felt at diagnosis continued to be experienced intermittently over the years, albeit less intensely. However, none of the parent's bar one had fully accepted the diagnosis or achieved closure. In contrast to a terminal illness where death would demarcate a clear ending, the chronic nature of type 1 diabetes means this point is not reached (Rifshana et al 2017). Emotional or stressful episodes such as illness or hospitalization as well as progression through adolescence were identified as triggers that evoked a resurgence of parental grief and inhibited closure. The transition from paediatric to adult diabetes services was identified as a particularly stressful time for parents, who felt there was a lack of emotional support from healthcare professionals. The Bowes et al study (2009) adds credence to the notion that the adolescent with diabetes is not the only individual within the family unit who may experience psychological difficulties, require support, and benefit from intervention strategies. A correlation has been demonstrated between parental perception of the diabetes burden in the family and parental depression, with maternal depression cited more frequently (Cunningham et al 2011). Haugsvedt (2011) also found that whichever parent had the highest burden of diabetes management within the family had higher levels of distress.

Establishing stable family functioning and clear role definitions related to responsibility for diabetes care can play an important role in preventing parental stress and has been shown to have an effect on glycaemic control (Whittemore et al 2012). For parents managing their child's diabetes treatment regime over a number of years there may be a shift in the perceived responsibility of roles as the child enters adolescence. The division of diabetes care and previously shared responsibility may be changed, either willingly or unwillingly by both parent and child, and this may cause tension within the family environment.

Relinquishing control of their child's diabetes management may be difficult and allowing them more autonomy may be stressful for the parent if their expectations are low and they anticipate negative diabetes outcomes such as hypoglycaemia. A study by Law et al (2013) looking at the role of self-efficacy, perceived consequences, family responsibility and adolescent-parent discrepancies, reported that parental confidence in adolescents' self-management had implications for parental diabetes distress and continued parental control mediated by fear was shown by Lindstrom et al (2011) to be linked to diabetes burnout. In order to avoid this outcome, Law et al (2013) advocated taking a family-perspective to diabetes care; encouraging parents to reduce their level of involvement, increase adolescent autonomy and therefore reduce the adolescent-parent discrepancies in responsibilities around diabetes tasks. They advised more open communication and negotiation to identify discrepancies and reduce the risk of a disproportionate diabetes burden on parents and parental distress.

Whilst interventions for reducing parental stress have been suggested in the literature around family functioning and family coping, there is a paucity of research that addresses this directly. Barnard et al (2010) conducted a systematic review on fear of hypoglycaemia in parents of young children with diabetes and suggested a structured education programme for parents on how to manage their child's biomedical and psychosocial needs could help reduce their own fear levels. Other studies have suggested screening parents for depression in a clinical setting in order to help families cope with diabetes (Whittemore et al 2012), but these may be time-consuming and costly for health professionals to implement.

2.8 The Internet and online support

As discussed, relinquishing control of their child's diabetes management may be challenging for some parents and the process of transition may exacerbate distress and feelings of negativity (Law et al 2013). Social support has been shown to mediate the effects of psychosocial distress for parents with a child with diabetes, and parents identified health care professionals and other parents with children with diabetes as strongly favoured sources of support (Whittemore et al 2012). However, during transition they may have reduced opportunities to interact directly with health professionals, as their child is encouraged to become more independent and take control of their diabetes management. Opportunities to meet with other similarly affected parents may also be reduced as their child moves to the adult diabetes services. This lessening of involvement can lead to a reduction in social support, which is a significant determinant of health for both the parent and the adolescent with a chronic disease (Gay 2004). Alternative sources of social support may be sought elsewhere by such means as the Internet.

The Internet has become an increasingly popular and accessible source of health-related information, advice and peer support through the use of Web2 applications including email, chat rooms, online forums and instant messaging (Boneva et al 2006). For parents of adolescents with type 1 diabetes, the Internet and in particular diabetes online forums and support groups have been viewed as a reliable and valuable tool, giving access to online environments where information about health and related issues is easily available (Balkhi et al 2014, Nicholas, Gutwin and Peterson 2013, Nordfeldt et al 2013). This type of communication has many benefits over more traditional face-to-face support group. They offer a sense of anonymity, greater accessibility with no geographical constraints, and individuals feel able to discuss potentially sensitive topics in perceived safety without fear of embarrassment or reprisal (Buchanan and Coulson 2007). In this way, the Internet is framed within a social context, particularly in the case of online support groups or forums, where a sense of camaraderie may be fostered and relationships formed which go beyond the scope of information seeking and into the realm of social support (Armstrong, Koteyko and Powell 2012). Research is limited in terms of examining the impact online support groups have on the parent of an adolescent with diabetes. However, there is evidence that suggests online forums may offer continuing professional information, informal peer knowledge and social support when the process of transition itself has reduced face-to-face communication with healthcare professionals that parents would previously have had access to (Holtslander et al 2012).

Balkhi et al (2014) assessed the demographics and motivations of 102 parents who used type 1 diabetes forums. They recruited participants via online forums who completed an online questionnaire that included quantitative and qualitative measures. These included the Pediatric Inventory for Parents (PIP), the Hypoglycemic Fear Scale, parent version (HFS-P) and the Michigan Diabetes Research and Training Centre's Brief Diabetes Knowledge Test (DKT). Two qualitative opened ended questions were posed to participants to clarify the levels of trust in other people in the Internet in general and more specifically on diabetes forums. The results suggested that participants placed a significant amount of trust in the information they received online as well as in the relationships formed online. Whilst this shows the potential online forums and communities have for disseminating information, it also highlights how the Internet and online forums may be a vehicle for promulgating misinformation (Hilliard and Hood 2015). Balkhi and colleagues (2014) reported that for those parents who participated in the study, forum membership, i.e. the number of diabetes forums accessed and the time spent online, was significantly related to the amount of parenting stress and hypoglycaemic fear they experienced. Despite this, the authors noted the relationship between hypoglycemic fear behaviors, parenting stress frequency, and forum membership alone did not provide enough evidence to draw causal conclusions or condemn online diabetes forums. Interestingly, the authors found that parents reported an increased knowledge about diabetes and perceived high levels of social support and trust when they participated in online diabetes forums despite the impact this could have on parenting stress and hypoglycemic fear. Here it appears the potential benefits of diabetes online support groups may outweigh negative aspects or consequences that participants may experience.

Similarly, Nicholas, Gutwin and Paterson (2013) examined parents' of adolescents with type 1 diabetes interest and perspectives regarding online diabetes support. Participants were drawn from three Canadian paediatric centres and included 29 parents and 31 healthcare professionals. The authors looked at the role of the Internet as a source of support and how this could be used to meet parents' need for information and support, which in turn could alleviate parental stress and anxiety. The participants felt that web-based information and support could be used to augment clinical care. Some concerns were raised about the safety and accuracy of information received online and the health care professionals who participated suggested the use of password entry into sites. Surprisingly, the parent group were resistant to this suggestion, favouring unrestricted access due to concerns about lost or forgotten passwords precluding their access to sites. They also advocated the inclusion of information that was targeted to more 'real life' concerns as well as diabetes issues. Participants wanted the online resource to be positive and growth orientated.

2.9 Summary

The transition from paediatric diabetes services to adult services has been shown in the literature to be a challenging time for both the adolescent and parent, as they may be required to make adjustments that could potentially increase levels of stress, effect their quality of life, levels of self-efficacy and health. Parents may need to adopt alternative coping mechanisms and strategies during this transition and it has been suggested that the use of the Internet and online forums as a source of information, guidance and support may have psychosocial benefits including improvements in coping ability, improved psychological well-being and empowerment (Mo and Coulson 2012, van Uden Kraan 2008).

Chapter 3: Online communities and support groups

3.1 Introduction

This chapter presents an overview of the literature regarding the Internet and online support groups. The first part of the chapter focuses on background information relating to the development and uptake of the Internet and social networking sites. Online support groups are then defined. The characteristics of these are examined, along with potential advantages and disadvantages, before considering who uses online support groups and their motivation for doing so. Moving through the chapter, the membership life cycle and levels of participation are addressed, to highlight the dynamic nature of online support groups, and how members' requirements from the online group may vary dependent on a variety of factors. The nature of online communication and the import of social support within health-related online support groups are discussed with attention drawn to the potential benefits those participating may experience. The literature reviewed in this chapter highlights the beneficial role online support groups have for people affected by chronic health conditions, but further research is required to address gaps in the existing research with regards to the social support needs and online support group experiences of parents of adolescents with type 1 diabetes.

3.2 Internet development and the adoption of social networking

Since its inception in the late 1980's, the World Wide Web (retroactively known as Web 1.0) as a component of the information technology revolution has helped facilitate economic and social change on an unprecedented scale. Intended to be a *'universe of network accessible information'* (Berners-Lee 1997), in 1998 only 9% of UK households had access. However, it is estimated there are now over 4.1 billion Internet users worldwide (International Telecommunication Union 2019), and in the UK, 96% of households are reported to have Internet access (Office for National Statistics 2020). The development of Web 2.0 technologies has been used to explain the exponential growth of users over the last decade (O'Reilly 2007). DiNucci first used the phrase Web 2.0 in 1999 as a means to explain the technological shift from the limitations of Web 1.0. Where Web 1.0 was the 'readable' phase of the World Wide Web with flat data, simply an information portal, the shift to Web 2.0 can be viewed as the 'writeable' phase. The advanced features of Web 2.0 changed the user role and experience from that of obtaining information to also being able to contribute and manage content, most evident in the innovation of social networking sites, for example Facebook, MySpace and Twitter, as well as electronic bulletin boards and discussion forums.

3.2.1 Social networking sites and online support groups

Social networking sites are founded on an interactive, user-based platform. Defined by Boyd and Ellison as:

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

Individuals can create an online 'profile' that can be personalised to reflect how they wish to be perceived or left ambiguous before connecting with others online. It is possible to access sites without having to interact with others, and people can choose to observe or 'lurk' without contributing (Edelmann 2013). Popular networking sites attract large numbers of users. It was reported that Facebook, founded in 2004, had over 2.5 billion active users across all platforms in 2019 (Statista 2019) and Twitter, launched in 2006, had over 152 million monetizable daily active users (Statista 2019). In the US 80% of Internet users aged 18 to 65 reported using at least one social networking site (Perrin and Anderson 2019). Similarly in the UK, 80% of adults who use the Internet say they have a social networking profile (Ofcom 2019). Social networking is a popular pastime, and the Taking Part survey published by the Department for Digital, Culture, Media and Sport (DCMS 2019) reported in 2018/2019 83.7% of adults had used social networking websites in the past twelve months. Of these, 52.5% had visited these websites several times a day, and almost 30% at least once a day.

Health-related and disease specific social networking sites have become more prevalent over the last decade, and it was reported that 63% of adult Internet users in the UK had used the Internet to obtain information appertaining to health issues in 2019 (Office for National Statistics 2019). Such accessibility, the development of Web 2.0 applications and the ubiquitous nature of social networking sites have led to the Internet becoming an increasingly popular source of health information for individuals with chronic conditions such as cancer, diabetes and HIV (Ayers and Kronenfeld 2007, Capurro et al 2014). People can use the Internet and social networking sites to communicate and interact with others with the same health condition or issues, who may have experienced similar life circumstances (Coulson and Smedley 2015, Fox 2011, Sillence and Mo 2014). This can take place in a number of ways, for example, via chat facilities, or discussion forums (also referred to as bulletin or message boards) that serve as a platform for health-related or disease specific online support groups.

3.2.2 Online support groups

In contrast to general social networking sites, health-related online support groups offer a more private, often condition specific collaborative community-based environment. They have been described as:

> *'a group of individuals with similar or common health-related interests and predominantly non-professional backgrounds (patients, healthy consumers, informal caregivers) who interact and communicate publicly through a computer communication network such as the internet, or through any computer based tool...allowing social networks to build over a distance*'. (Eysenbach et al. 2004, p.1).

Online support groups can generally be distinguished as either synchronous or asynchronous. Synchronous online support groups offer live, real time interaction and communication between members. This is most evident in chat rooms, instant messaging applications and virtual reality environments where there is a high degree of immediacy in the communication that takes place. This makes it necessary for those participating to be more aware of their response time when directing comments to the relevant person, which can impact on the wording and length of reply (Boniel-Nissim 2016). By comparison, the communication that takes place in asynchronous online support groups is not as dynamic. Here a more static environment is characteristic, with content changing less frequently due to the structure of the forum.

In asynchronous online support groups discussions are organised into hierarchical '*threads*', generated when an individual posts an initial message. This may be an introductory post from a new member, or a question, observation or experience someone wants to share with the group. Other people can read this message at their convenience, and the nature of asynchronous communication gives them the opportunity to compose and edit their responses before posting. These replies can generate further responses from other people, which adds to the tree-like structure of the thread, with the original post displayed at the top (Petrovčič, Vehovar and Žiberna 2012). Unlike real-time communication that takes place in synchronous online groups, where questions are answered immediately, messages posted in asynchronous online groups may not receive a prompt reply. The delay before someone responds to a post can range from minutes to months (Coulson and Greenwood 2012, Ainscough et al 2018).

3.3 Looking for health information online

Individuals can use search engines to find the appropriate online group or forum that best meets their needs. De Choudhury and colleagues (2014) examined how Internet users sought health information online, either via search engines (e.g. Google, Yahoo, Bing) or social media, in this case Twitter. 165 conditions were identified and the top 20 included cancer, pregnancy, multiple sclerosis, diabetes, stress, stroke, autism, heart disease and constipation. Using both large-scale log analysis of Twitter's Firehose stream over a period of 15 months and a survey of 210 people, the authors found that over 94% of respondents reported using a search engine to seek health-related information in comparison to 19% who reported using Twitter. They noted the respondents' motivations for seeking health information and the most common was to identify treatment options (59%), followed by diagnosis of a health condition (26.8%) and general understanding of a health condition or procedure (20.8%). Seven percent of the recalled searches were motivated by understanding medications or learning about they worked, and 6% of searches were related to lifestyle information for chronic concerns, in particular information for managing aspects of diabetes.

For conditions perceived to have a social stigma, there was a marked difference between how respondents searched for information. Significantly more preferred to use a search engine rather than Twitter, however this did not preclude people sharing some information on stigmatic conditions via Twitter. The authors suggest this may be indicative of people's propensity to view social media as a platform to share their thoughts and experiences of the symptoms and effects of their condition rather than a platform for information, education or support.

The De Choudhury et al study highlights the popularity of search engines and social media as tools for seeking and sharing information about health conditions and concerns. Whilst it does not identify which sites respondents accessed, the results show that search engines are useful for identifying online health communities and support groups, shown to be key venues for social support (Coulson and Malik 2012, Rains and Wright 2016, Wright and Bell 2003).

3.4 Potential advantages and disadvantages of online support groups

A review of the literature regarding research on health-related online support groups has identified a number of unique characteristics observed in online support groups, including an absence of temporal and geographical barriers, a sense of anonymity and greater accessibility with asynchronous text-based communication (Wright and Bell 2003). Furthermore, online support groups can provide access to a larger, more diverse support network, as in general there are no restrictions on the number of people participating in the group. Whilst these characteristics may be advantageous for people using online support groups, possible disadvantages of this form of communication have been noted (Bartlett and Coulson 2011). These will be considered in more detail in the following section.

3.4.1 The potential advantages of online support groups

3.4.1.1 Lack of geographical and temporal barriers

Face-to-face diabetes support groups have been shown to have physiological and psychological benefits for individuals with diabetes and their families (Kichler et al 2013, Markowitz and Laffel 2012, Pate et al 2015). Nevertheless, participation may not always be a convenient option due to the lack of available groups in the right location, the timing of meetings, or existing commitments such as school, college or work (Creedy et al 2005, Pelentsov et al 2016). Therefore, the ability to communicate with other people without leaving home is advantageous, particularly so for people with mobility issues or affected by unpredictable chronic conditions such as MS or fibromyalgia (Braithwaite, Waldron and Finn 1999, Chen 2012, Colombo et al 2014). Online support groups, unlike organised physical groups, may be more opportune, and more easily accessible when required, day or night. Being able to obtain information or advice 24 hours a day, outside office hours when healthcare professionals may not be available, is a characteristic of online support groups that parents of children with diabetes have been shown to value (Merkel and Wright 2012, Holmström, Häggström and Söderberg 2018).

Not constrained by geographical or temporal barriers, online support groups allow members access to a larger more heterogeneous mix of people, with differing perspectives and experiences (Coulson and Malik 2012). People can electronically search for and connect with others who share the same health concerns or conditions from geographically diverse locations. This is particularly beneficial for individuals with rare conditions or their parents and carers who may feel isolated, and unable to find and communicate with people experiencing the same problem in their area (Glenn 2015, Lasker et al 2006, Oprescu et al 2013).

3.4.1.2 Anonymity

In comparison to face-to-face groups, online support groups can afford individuals an increased level of anonymity (Attard and Coulson 2012, DeAndrea 2015, Venner, Galbraith and Fullwood 2012). It is at the discretion of the individual to decide how much information they choose to disclose about themselves or their condition. In a grounded theory study by Rasmussen et al (2007), 20 young women with diabetes reported using Internet chat lines and forums to communicate with other people with diabetes. Whilst websites and forums were seen as places to find out information about diabetes and 'bounce ideas off others', the ability to remain anonymous was there if required, and this was found to be a key strategy that provided a feeling of control and autonomy whilst managing life transitions (Rasmussen et al 2007).

Anonymity can be advantageous when choosing to disclose sensitive information or discuss topics that have a stigma attached (Chang and Bazarova 2016, Mo and Coulson 2014, Wang et al 2017, Wright and Rains 2013). Vilhauer (2014) compared the experiences of women with metastatic breast cancer in online and face-to-face support groups and found that online support was deemed beneficial whilst adjusting to a diagnosis of cancer, as they could receive support without confronting evidence of physical disability in others or engage in discussions about dying before they felt able to deal with it. As Kang (2017) states:

> *'When people want to talk about topics that are socially undesirable or sensitive, individuals strategically use anonymity in order to avoid judgment from others. People who prefer to be anonymous are likely to talk about those stigmatized issues more freely than are identified others'* (p.7).

Likewise, a lack of physical proximity coupled with a sense of anonymity and lack of physical cues can lead to greater openness about feelings (Tanis 2008) or higher levels of self-disclosure, referred to as the online disinhibition effect (Suler 2005). Whilst this may empower those who feel marginalised by their health condition to disclose sensitive information they would not otherwise share in a face-to-face environment (Hixson et al 2015, Shoebotham and Coulson 2016), there is some evidence which suggests the disinhibition effect may not always be so benign (Lapidot-Lefler and Barak 2012).

3.4.1.3 Asynchronous communication

As previously discussed, there are unique advantages of online support groups delivered in an asynchronous format. A major benefit of asynchronous online support groups is that unlike face-to-face groups that meet at a scheduled time, the majority are available to access 24 hours a day. Studies investigating online support groups for a variety of health conditions have identified this characteristic as one that members appreciate (Malik and Coulson 2008, Coulson et al 2016, Lovatt, Bath and Ellis 2017, Schook et al 2014). The convenience and flexibility of around-the-clock online access means members can not only search for information as and when needed across discussion boards, but also can also offer reciprocal advice and support to other members (Loane and D'Alessandro 2013, Pan, Shen and Feng 2017). It should be noted that whilst some sites may have a chat facility that allows for real time discussions, the majority of interactions on health-related online forums are textual and asynchronous. This means that after reading posts, members can consider and reflect on the information presented before responding, and this can be edited as needed (Vilhauer 2009).

3.4.1.4 Locating similar others

People use health-related online support groups to search for other people with the same condition, or who are undergoing or have undergone similar experiences (Barak, Boniel-Nissim and Suler 2008, Coulson 2013, Glenn 2015). Those participating in condition-specific online support groups have reported a sense of familiarity and acceptance, and people may feel a sense of normalcy by learning how others have coped with the same condition (Lowe et al 2009). It has been shown that people using health-related online support groups look for information and support from others most like themselves in terms of age, gender and health condition. The rationale for this being a sense of commonality and familiarity, and people who in a similar circumstance or are sharing similar problems are more likely to be empathetic and understanding towards those looking for information or support (Bond and Ahmed 2016, Sillence 2010). Furthermore, people can look to connect with 'experiential experts' in online support groups (Tanis 2008). These are members whose first-hand experience and knowledge can provide a deeper, more personal perspective of the health condition, making them an appurtenant source of information and emotional support (Tanis, Das and Fortgens-Sillmann 2011, Angouri and Sanderson 2016).

In order to connect with similar others online, some people will initially introduce themselves to the group, or post a request for information and wait for a response. Alternatively, some will carry out a historical search of the boards to gain information about how other people in similar situations to their own cope and deal with their health condition. In this way, these online groups can be used for social comparison (Batenburg and Das 2015, Davison, Pennebaker and Dickerson 2000). Finding others who are similar can be particularly important when people feel lonely, different or misunderstood.

This perceived similarity and the feeling of belonging to a larger community is part of a basic need to belong (McKenna and Bargh 1998), and can go some way to reducing feelings of isolation or loneliness (Shoebotham and Coulson 2016, Powell 2003). Litchman, Rothwell and Edelman (2017) found that older adults with diabetes who used an online support group reported online relationships forged with strangers with diabetes gave them a sense of belonging to a community. This encouraged them to seek information from *'diabetes elders'*; people who had decades of diabetes experience, and to share their experiences with others in the group in similar circumstances who could empathise. Within health-related online support groups empathetic exchanges have been found to be stronger and more evident when there is a connection by similarity in the group, be that a specific health condition, experiences or emotions (Hargreaves et al 2018).

3.4.2 Potential disadvantages of online support groups

3.4.2.1 Anonymity

A disadvantage of online anonymity is that it could lead to deindividuation. Here a person may lose their sense of identity and become immersed in the identity of the online group (Festinger et al 1952). This deindividuation Internet behaviour and the reduced visual, auditory and context cues characteristic of online communication are believed to lower certain people’s inhibitions when using online groups (Joinson 2007), most notably among young people (Valkenburg and Peter 2011). This may play out as online aggression and abusive behaviour (referred to as flaming), which can be detrimental to individuals or the group (Dyer et al 1995). Flaming may manifest in aggressive or abusive language, negative comments or planting deliberately false or malicious advice (Derks et al 2008). Lapidot-Lefler and Barak (2012) considered the impact of anonymity in relation to toxic online disinhibition and concluded that previous definitions of anonymity did not fully take into account the importance of certain factors that characterise the online environment, specifically invisibility and the lack of eye contact, which makes the most powerful contribution to the online disinhibition effect. From this they proposed a new concept, online sense of unidentifiability. Extending previous definitions of online anonymity to take into account this additional concept may go some way to explaining negative online disinhibition.

3.4.2.2 Asynchronous communication online

What is not guaranteed with asynchronous communication in an online support group is an immediate or timely response to a post (Wright 2002). Members can ‘bump’ posts to raise their profile and bring them to the attention of other users, but a delay in receiving feedback to requests can be frustrating, particularly if the original post was an urgent request for information or support (Pfeil et al 2009, Clifford and Minnes 2013). Conversely, the amount of time spent online responding to requests or following discussion threads can be lengthy, challenging and may cause stress. This may be further compounded for those users who feel they are not particularly eloquent or loquacious, but feel they should respond, and those who do not communicate well using the written word may be disadvantaged (Finfgeld 2000).

3.4.2.3 Lack of verbal cues

While the lack of face-to-face communication in online support groups offers group members privacy, this may also allow for the possibility of misinterpretation or misunderstanding of the meaning of textual messages. This stems from the lack of non-verbal cues, exemplified in the 'lack of social-context cues' hypothesis by Sproull and Kesler (1986). Without being able to see facial expressions or hear tone, pitch or inflection as would happen during a spoken face-to-face conversation, people might struggle to distinguish the true meaning of a sentence. Concepts like irony or sarcasm that rely very much on verbal cues could be lost or conversely incorrectly assumed (Preece and Maloney-Krichmar 2003). A way to compensate for this ambiguity is by the use of typographic sideways symbols. Sanderson (1994) categorised numerous of these, more commonly referred to as 'emoticons' or 'smileys' or 'relational icons', for example, happy 8-) or sad faces :-(). This 'paralanguage' includes lexical surrogates that describe nonverbal behaviours used to indicate mood states (Carey 1980). These include the written form of nonverbal vocalizations such as 'hmmmmm' or oooohhh', the use of intentional misspellings, and hyperbolic repeated punctuation marks, for example '!!!!!!!!!!' to stress the point in a sentence. The use of emoticons and abbreviations such as 'LOL' meaning 'laugh out loud', has become commonplace on online forums, and is recognised by forum members as a way of showing an emotional response (van Uden-Kraan et al 2008, Scott et al 2014).

A study by Kirk and Milnes (2016) explored how online peer support was used by young people and parents to support self-care in relation to cystic fibrosis. The authors analysed posts from the online forum based on a cystic fibrosis charity website. They noticed there were occasional misunderstandings due to the absence of non-verbal communication but the regular use of emoticons appeared to compensate for this. However, paralanguage can be quite complex or specific to a particular online forum. Pfeil et al (2009) noted that older users were uncertain about how to use paralinguistic expressions and reported feeling uncomfortable. With an ageing population and an increasing reliance on the Internet and online services, it is encouraging to note that some forums have compiled glossaries to enable new members to become integrated more quickly (van Uden-Kraan et al 2008).

3.4.2.4 Misinformation and negative content

Other disadvantages levied against health-related online support groups include the possibility of incorrect or misleading information and reading about the negative experiences of others (Attard and Coulson 2012, Malik and Coulson 2010, Teasdale, Muller and Santer 2017). These can cause concern for users, with misinformation affecting a member’s perception of source credibility (Jin et al 2013). Yet, when van Uden-Kraan et al (2008) analysed a sample of 1500 posts from fibromyalgia, breast cancer and arthritis online support groups, they found no evidence of potentially dangerous information within the posts. Expressions of negative emotions such as fear or anger were also limited, evident in less than 5% of all posts. Esquivel, Meric-Bernstam, and Bernstam (2006) reported that only a very small number of messages posted on a breast cancer online support group contained unreliable or incorrect information, and these were quickly flagged and corrected by other group members. Likewise, Armstrong, Koteyko and Powell (2012) did not find evidence of inaccurate information being posted on a diabetes online forum for adults. Posts considered controversial were quickly addressed by other users, demonstrating the aptitude of online support groups to 'self-police'. This is something typically performed by group moderators to ensure the safety of users and to reduce the risk of inappropriate or inaccurate medical information (Hardey 2001). Moderators will customarily provide guidance about what are appropriate forms of information allowed to be distributed on the online group and enforce the rules by editing or deleting those inappropriate messages (Mudry and Strong 2013, Wright 2009, Smedley and Coulson 2017).

A study by Coulson and colleagues (2016) found that reading messages disclosing details about others' negative experiences in an online support group for people with chronic sleep problems was challenging for some group members. They considered these posts to be upsetting, distressing and unhelpful, and reported they had a negative impact on their well-being. Similar findings have been identified by Griffiths, Calear and Banfield (2015) investigating the benefits of an online support group for depression. The authors reported some members experienced negative emotional changes associated with reading about other people’s problems. If posts are too painful for some members to read or cause emotional distress and anxiety, they will try to avoid these (McKechnie, Barker and Stott 2014). If this strategy proves difficult, members may feel they have no other alternative than to leave the online group.

3.5 Who uses health-related online support groups?

3.5.1 User characteristics

The demographic characteristics of individuals who use the Internet for health-related information and support have been reported as predominantly white, female, educated with a college degree, employed and of a younger age (Fox and Duggan 2013). These are also shown to be associated with levels of participation in online support groups (Owen et al 2010). A survey of online support group use among people living with HIV/AIDS showed that frequent users were more likely to be female, younger and single in comparison to infrequent users of online support forums (Mo and Coulson 2010). Huber and colleagues (2017) compared face-to-face support groups for prostate cancer with online support groups and reported online support group members belonged to a higher socioeconomic group and had higher levels of education. Both are linked to higher levels of computer ownership and computer literacy (Pfeil et al 2009, Beck et al 2014). Likewise, people with higher educational qualifications are more likely to have access to the Internet, and arguably more able to negotiate and disseminate the diversity of information that the Internet affords (Prestin, Vieux and Chou 2015). There are apparent disparities in those who report using online support groups, and a concern raised by researchers is that these socioeconomic and demographic factors lead to disparities in seeking health information online (Feng and Xie 2015).

Previous studies have identified gender differences between how male and female forum members use and communicate on online support groups. Prostate cancer survivors were shown to use online support groups mainly to gather information in comparison to breast cancer survivors who used the groups as sources of emotional support (Blank et al 2010, Seale, Ziebland and Charteris-Black 2006). In a systematic review of gender differences in online health-related support groups, Mo, Malik and Coulson (2009) found that whilst there was some evidence of gender differences between male-specific and female-specific groups, this was not as apparent in mixed gender groups. Similar findings were reported in a later study by Liu, Sun and Li (2018) examining gender differences in a Chinese diabetes online support group. It would appear the specifics of the disease or the stage of the disease can have more of an influence on online support group membership and use than gender. Nevertheless, health-related online support groups are not just the bastions of people with an illness or disease. Caregivers, family members and friends of people with long-term health conditions have all been shown to use health-related online support groups for information, advice and support (Fox and Brenner 2012, Parker Oliver at al 2017).

Family caregivers of people with a variety of chronic and long term conditions have reported facing physical, emotional and social problems (Bartolo et al 2010, Im et al 2010, Klemm and Wheeler 2005), and some have described the psychological burden as a 'living bereavement' (Kiecolt-Glaser et al 1991, p.1). The user characteristics of caregivers using health-related online support groups are similar to those of patient users in terms of a reported higher level of education, higher socioeconomic status and being predominantly female. However, the age of caregiver users is more variable and contingent on the age of the person being cared for. This reiterates the relevance of the disease or condition when identifying user characteristics. As an example, a study by Kim (2015) exploring health-related Internet use among caregivers of persons with dementia found the average age of the caregiver to be above 50. This may be explained by the fact that dementia is more prevalent in an older age group, and many caregivers are the patient’s spouse or adult child (Lewis et al 2014).

With regards to parents of a child with a chronic condition such as diabetes, there is a reported predominance of mothers using health-related online support groups for information and emotional support. This correlates with reported higher levels of maternal stress in comparison to paternal stress for parents with a child with diabetes (Haugsvedt et al 2011). However a study by Maas-van Schaaijk et al (2013) looking at the inter-relationship between paternal and maternal stress, metabolic control and depressive symptoms in adolescents with type 1 diabetes found that fathers of adolescents with diabetes reported significantly more parenting stress than fathers in a comparison group whose children did not have diabetes. A systematic integrative review on Internet-based peer support for parents (Niela-Vilén et al 2014) found that the majority of the 38 studies they identified focused on online support groups between mothers or both parents, with mothers found to more active users of Internet based support groups. Mothers were more likely to use online support groups to search for and share information based on their own experiences, with emotional support considered a key benefit. This gender difference between parents and online support group membership could be explained as a result of a more nurturing characteristic of women, with mothers shown to be more proactive and involved in all aspects in their child's diabetes management than fathers (Dashiff et al 2009, Hanson et al 2012, La Greca 1998, Wennick and Hallström 2007).

Identifying user demographic characteristics supports the view that participation in health-related online support groups can vary according to age, gender, education, socioeconomic status and the disease in question (Atkinson, Saperstein and Pleis 2009, Gooden and Winefield 2007, Mo and Coulson 2010, Owen et al 2010, Im, Lee and Chee 2011). However, this does not explain what motivates people to use health-related online support groups and this will be discussed in greater detail in the next section.

3.6 What motivates people to use health-related online support groups?

Individuals with a chronic disease such as asthma, diabetes, arthritis and cancer have been shown to be more likely than their counterparts to use health-related online support groups (Fox and Duggan 2013, Owen et al 2010). For some severe life limiting diseases, such as terminal cancer, it has been shown that family members of the patient were more likely than the patient themselves to access and participate in online support groups (Ye 2014). Diseases that have a social stigma attached such as HIV/AIDS, anorexia or mental health problems have also been shown to be the types of conditions that people will look online for support (Davison, Pennebaker and Dickerson 2000, Nimrod 2013, Wang et al 2017, Wright and Rains 2013). Similarly, this applies to conditions that can have an effect on people’s physical appearance, such as polycystic ovary syndrome (PCOS), psoriasis, or burn injuries (Holbrey and Coulson 2013, Idriss et al 2009, Mirivel and Thombre 2010). Rare diseases by their isolating nature may also make it difficult for patients and their families to find support, and online support groups can provide a way of accessing an often hard-to-reach population (Kauw et al 2015).

A phenomenological study by Glenn (2015) found that families living with Alagille syndrome (ALGS), a rare genetic disease that can affect the heart, liver, kidneys and eyes, experienced similar psychosocial reactions to families living with a more prevalent chronic disease, such as diabetes. All participants in the study were mothers and they reported using the Internet and online support groups to obtain informational and emotional support as a means to manage their chronic sorrow, a concept first proposed by Olshanky (1962) to describe the normal pervasive psychological response in the suffering of parents dealing with a mentally disabled child. The concept of chronic sorrow has been further developed since its initial conceptualisation. More current research continues to acknowledge the importance of social support from other people for families whose child has a chronic condition such as diabetes, epilepsy or cerebral palsy, helping them cope in relation to chronic sorrow (Bowes et al 2009, Hobdell et al 2007, Fernández-Alcántara et al 2015).

Analysis of the interview data from 16 mothers in the study by Glenn (2015) identified four themes: i) connectedness, ii) empowerment, iii) online triggers and iv) seasons of online use. Connections to an online support group were seen as a 'lifeline' given the rarity of the disease and a sense of similarity and belonging was fostered. This allowed information and emotional support to be sought and shared (Coulson and Greenwood 2012) and as a result, the mothers felt more empowered (Dolce 2011). They were also aware that online communication could trigger chronic sorrow and unpleasant feelings due to searching for information, reading about other parents' experiences or the death of a child with ALGS (Gundersen 2011, Tozzi et al 2013). However, the rarity of ALGS led the mothers to engage in heavier online communication to meet their information needs.

The mother's engagement in online support groups varied by 'season'. This was a term used to describe a period of time and the experiences families had with the disease during this. There could be 'good' or 'bad' seasons which correlated with the choice and frequency of online communication. A bad season was when problems occurred and more online communication and support was needed, and this appeared to be related to the trajectory of the disease. Mothers of younger children used less online communication when their child was stable and mothers of older children used online communication less for information and more to support parents of newly diagnosed children. Online communication frequency was influenced by knowledge and previous experience, and this was consistent with the Nordfeldt et al study (2013), which elicited the views of parents of adolescents with type 1 diabetes about their information and communication needs and Internet use.

Whilst the illness characteristics and trajectory differ from ALGS, parents with a child diagnosed with type 1 diabetes also experienced chronic sorrow and wanted information, education and social support (Bowes et al 2009). Interacting with other people who shared similar experiences and had similar concerns was seen as a way to reduce parental stress and empowered them in supporting their child's self-care (Grey et al 2011).

Some people feel more comfortable interacting in online health support groups for reasons discussed previously. Research by Chung (2013) identified factors leading to the preference of social interaction in online support groups over offline interaction. 158 users from 4 health-related online support groups (2 cancer and 2 diabetes groups) completed an online survey to measure social interaction preferences (Caplan 2003), depth of relationships in online support groups (Pierce et al 1991, Pierce et al 1997), satisfaction with offline social support (Sarason et al 1987) and satisfaction with medical care (Marshall et al 1993). The results showed that certain users of online support groups are more disposed to develop a preference for online social interaction. People not satisfied with the offline support they received were more likely to turn to online support groups for social interaction, and this was true for those who developed deeper social relationships in online support groups.

The findings also show that participants were not using online support groups to make up for unsatisfactory care from healthcare professionals. Rather, they were using them to gain additional information and advice about their health condition, which could enable them to contemplate and consider their current medical treatment. In this sense, health-related online support groups are a complementary resource for health information and education (Lee 2008). This is increasingly acknowledged by health professionals who are becoming aware of the potential of online support groups as a way of engaging with patients with diabetes in a contemporary and more accessible way (Gilbert et al 2012), that is valued by patients. The synergistic quality of online support groups could appeal to people who are looking for information and support from multi-agencies at different levels which suit their needs at a particular time, and this may be reflected in how they participate on forums and support groups and how that participation starts and develops.

3.7 Membership life cycle and levels of participation

3.7.1 Membership life cycle

The literature around online support groups has identified that members may hold different roles within the group, and these are liable to change or evolve during the membership life cycle (Kim 2000, Nimrod 2012, Sonnenbichler

2010). A conceptual five-stage linear model of online community involvement was proposed by Kim (2000). People first access the online community as 'visitors', observing and assessing the activity of other members while they consider joining it. Some visitors will leave the community after a few visits, while others register and become 'novices'. These members will begin to engage with the community, often by way of an introductory post. As their level of activity and interaction increases some novices progress to become 'regulars'. These are more established members who communicate efficiently with other members, and over a period, some may progress to the role of 'leaders'. Leaders are viewed as having a more authoritative and supportive position within the group. In the final stage of the life cycle, members become 'elders.’ These are long-time regular members and veteran leaders, some of whom may not contribute as much as they once did, but are still knowledgeable and respected by other members.

Building on Kim's (2000) model, Sonnenbichler (2010) proposed that after visitors become novices they do not necessarily become active members and then leaders. Some become passive members, with low levels of activity who use the group mainly for information, while others known as 'trolls' may post information with the intention of being disruptive. Unlike Kim's linear model, Sonnenbichler suggests bi-directional mobility exists between the various roles, and in the context of health-related online support groups, changes may occur in response to members’ particular needs and the perceived benefits of participation. Addressing this, Nimrod (2012) proposed the membership life cycle starts with an individual feeling distressed, the catalyst that motivates them to initially connect with the online support group. From 'distressed newcomers', members become 'active help receivers' who look for information and share content with other members, or 'passive followers', preferring to observe the online discussions. For some members, their initial distress will diminish over time and at this stage they are 'relieved survivors'. More veteran members may access the online group less frequently, deciding they have as much information as they need or they no longer require support. At this point, some will leave the group, becoming 'moving-on quitters'. Others will continue to visit the group, albeit not as often, to help others as 'active support givers', a role similar to 'elders' described by Kim (2000).

3.7.2 Levels of participation

One of the benefits of online support groups is that they can have unlimited numbers of members. However, not every member is an active participant. A survey carried out by O'Neill et al (2014) of 1000 Internet users in the UK, investigated how often respondents accessed a health-related online support group and explored if they actively shared health information with others online. Over a quarter of all respondents (27.8%) reported participating in an online support group, with a similar proportion (23.1%) reporting they had used the online support group to share details of a medical condition or problem to get help from other group members. 22.2% of those surveyed were unaware this was something they could do. Similarly, in a study investigating the characteristics of smokers in an online smoking cessation group, it was found that over 84% of registered members had never posted (Selby et al 2010) and in a prostate cancer online support group 5% of members accounted for 70% of the messages posted (Huber et al 2011). The '1% rule', stemming from the cyberculture and digital marketing literature (Nielsen 2006) has been used to explain this type of uneven distribution, and hypothesises that 90% of members observe but do not participate, 9% rarely contribute and 1% are responsible for the majority of posts. This 90%, 9% and 1% have also been referred to as lurkers, contributors and super-users (van Mierlo 2014). O'Neill (2014) noted that that the 1% rule was contextual and if people were members of multiple online groups their participation behaviour could vary between them. Group members could also be more likely to post if they felt they were making a contribution that was original or were posting about a subject had not been covered by other members (Adams 2011).

Identifying why members belong to either the lurkers, contributors or superusers (van Mierlo 2014) category in online communities has proved challenging, particularly with reference to lurkers. This category of member has been described as people who read messages posted by others, but do not post and not make their online presence known (Walther and Boyd 2002). This title has a somewhat pejorative overtone, but 'lurking' has been viewed as acceptable behaviour in online groups as it is neither harmful, nor a strain on resources (Nonnecke and Preece 2003). It allows people to gather information covertly without participating and it may also facilitate a feeling of empathy due to reading about other members experiences, which is a similar benefit experienced by members who actively contribute (Walther and Boyd 2002).

Three key motives were suggested by Kollock (1999) to explain why some members are more active contributors in comparison to others. These were anticipated reciprocity, where a group member offers help with the expectation this will be reciprocated when required, a sense of efficacy, where members provide information or support to other members believing they are providing a service to the group, and thirdly, to gain recognition and foster a reputation within the online community.

In contrast to the three motives offered by Kollock (1999), Fox and Jones (2009) found that individuals were more likely to obtain information and support from online health groups than offer to help other users, resulting in an 'undersupply of discretionary information' (Connolly and Thorn 1990, p.221). Two major reasons were identified following research on the psychological aspects of why certain users may not contribute on forums. Firstly, a lack of social responsibility for contribution, and secondly, anxiety about how other forum users would react to their posts (Preece, Nonnecke and Andrews 2004).

3.8 The nature of online communication

With the development of Web 2 technology and the widespread uptake by the general population, researchers have become interested in the implications of online groups for social support processes (Wright et al 2011). The preponderance of discussions on online support groups relates to illnesses, medical conditions and associated topics such as diagnosis, treatment, self-management and long-term prognosis (Chen 2012, Flower, Bishop and Lewith 2014, Loane and D'Alessandro 2013, van Uden-Kraan et al 2008). Nevertheless, online discussions are not just limited to these and more non-disease topics are covered as well as more personal and emotional subjects, as a significant number of people seek social support online.

3.8.1 Social support and social networks

Social support is a complex and multi-faceted concept. Despite a substantial body of research investigating this concept since the publication of seminal works in the 1970's (Caplan 1974, Cassel 1976, Cobb 1976), there appears little consensus as to any singular theoretical and operational definition (Hupcey 1998). As House (1981) noted:

> *'social support is a concept that everyone understands in a general sense but it gives rise to many conflicting definitions and ideas when we get down to specifics.'* (House 1981, p.13)

In an attempt to identify a definition of social support that could be applied to the experience of being a new parent, Williams, Barclay and Schmied (2004) carried out a critical review on an extensive body of academic literature spanning four decades. From their preliminary study the authors reported evidence of many and varied definitions. Inconsistencies in their use were noted, and definitional constructs bore little direct relevance to the contexts in which they were used for research purposes. The authors put forward a theoretical argument that social support must be defined in a contextually specific way for it to be relevant. Furthermore, conceptual ambiguity around social support has research implications, and a clear definition is essential to operationalizing social support so that valid and appropriate measures are used (O'Reilly 1988).

Social support has been generally defined in the literature as it affects health and well-being as referring to the perceived comfort, care, esteem or help one individual receives from another (Wallston et al 1983). It has been put forward that social support as a resource is given often with an expectation of reciprocity within social networks (Cohen and Syme 1985). It is important to distinguish between social support and social networks, often used interchangeably as concepts, despite theoretical recognition of their differences (O'Reilly 1988, Gottlieb and Bergen 2010). Social networks can be defined as:

> *'all those people with whom we have ongoing relationships and through which individual people are linked into groups and society.'* (Cleak and Howe 2004, p.21).

Depicted by Gottlieb (1983) as an interactive 'field of persons' providing the 'give and take' of helpfulness and protection, social networks may vary in terms of a number of structural characteristics. These can include size (the number of people in the network), homogeneity (similarities between people) and reciprocity (to what extent interactions are reciprocal) (Berkman et al 2000). Whilst differences between social networks have been noted in terms of size, the presence of a large network is not indicative of large amounts of social support (Kahn and Antonucci 1980). Considered to be of more consequence are the number of relationships or 'ties' in a network, and the strength of those (Wright and Miller 2010). Grannovetter (1973) describes the strength of a tie as:

> *'the combination of the amount of time, the emotional intensity, the intimacy (mutual confiding) and the reciprocal services which characterize the tie.'* (Grannovetter 1973, p.1361).

Distinguished as either a 'strong' or 'weak' tie, 'strong ties' are identified as those that develop from intimate relationships such as with family members, partners or friends. 'Weak ties' include neighbours, casual acquaintances, co-workers, members of face-to-face support groups, and since the emergence of the Internet, online support groups (Wright and Bell 2003). Whilst there are positive benefits associated with strong ties such as companionship and emotional provision (Wellman and Wortley 1990), weak tie networks serve several functions, including access to more diverse information, facilitating disclosure of risky or stigmatised topics and more objective advice (Adelman et al 1987, Wright and Bell 2003).

To reiterate, a social network is the structure of an interactive process that gives rise to social functions including social influence, social comparison and social support (Heaney and Israel 2008). Past empirical research has identified positive and significant relationships between social support, health status and health behaviours across a range of conditions including cancer, diabetes, Crohn’s Disease, ulcerative colitis and heart disease (Britt 2017, Cámara et al 2011, Gallant 2003, Miller and DiMatteo 2013, Nausheen et al 2009). This literature has also demonstrated higher levels of social support being related to improved psychological health (Illangasekare et al 2014, Lakey and Orehek 2011, Şahin and Tan 2012, Ng et al 2015).

Online support groups have been shown to provide social support that mirrors many of the therapeutic benefits of face-to-face support groups (Preece 1999). The rapid growth and preponderance of online support groups over the past decade for a multitude of health conditions endorses the assertion that 'online social support for patients and families will be an essential comprehensive approach to health care' (Weiss et al 2013, p.970). Being mindful of the point made by Williams, Barclay and Schmied (2004) to define social support in a contextually specific way for it to be relevant, Walther and Boyd's definition of online social support addresses both:

> *'the exchange of verbal and non-verbal messages conveying emotion, information, or referral, to help reduce one's uncertainty or stress'* (Walther and Boyd 2002, p.154).

Across the social support literature three categories of social support have been identified, namely emotional support, informational support and instrumental support (Cohen 2004). Other researchers have described and defined aspects of social support. Cutrona and Suhr (1992) proposed the Social Support Behaviour Code (SSBC). This identified five main categories of social support: (1) informational support (providing information or advice, factual input and feedback); (2) emotional support (this includes expressions of love, concern, empathy and reassurance); (3) network support (this entails a sense of belonging to a group who share similar concerns or experiences); (4) esteem support (showing regard and confidence in abilities or personal qualities); and (5) tangible assistance (this includes offering to provide goods or services).

Studies employing content analysis have identified these categories as being conspicuous in online support groups (Rodgers and Chen 2005, Donelle and Hoffman-Goetz 2008, Coursaris and Lui 2009, Coulson and Greenwood 2012), with informational and emotional support at the forefront of the exchanges between members (Eichhorn 2008, Evans, Donelle and Hume-Loveland 2012, Fukkink 2011, Lasker, Sogolow and Sharim 2006). A study by Coulson, Buchanan and Aubeeluck (2007) looking at the communication between members on an online support groups for Huntington disease found that emotional support was identified in over 50% of messages, and informational support was evident in almost 60% of messages. Greene et al (2011) identified the 15 largest Facebook groups that focused on diabetes management and analysed wall posts and discussion topics. They found that requesting diabetes specific advice and receiving emotional support were the most common topics among users, with over two thirds of the posts being about diabetes management strategies and almost a third were posters giving emotional support to other members. In a related study, Holtslander et al (2012) carried out a needs assessment of parents and service providers of adolescents with type 1 diabetes to identify the key elements for designing an online support intervention. Caregivers reported preferences for both informational and emotional support-based content, which substantiates previous research regarding the importance placed on these categories of support in online support groups. Similarly, using content analysis of messages posted on a newly launched Complex Regional Pain Syndrome (CRPS) online discussion forum, Smedley and colleagues (2015) reported emotional support to be the type most commonly found in messages, present in over 73%, followed by informational support found in almost 35% of the messages analysed.

Other research using content analyses to analyse online support group messages has shown informational support as being more prevalent than emotional support. In a study exploring discussions in an online adult diabetes community, Armstrong, Koteyko and Powell (2012) analysed posts on the discussion board and found that whilst emotional support was apparent and acknowledged, informational support was more prevalent. Discussions within the community were focused on diabetes related issues including self-management, new developments in treatments and coping. Similar results were found in Loane and D'Alessandro's (2013) study of an online health community for patients and carers affected by Amyotrophic Lateral Sclerosis (ALS), where content analysis of messages posted by both groups found informational support to be more prevalent than emotional support. Likewise, in their analysis of people with head and neck cancers' use of online support groups, Algtewi, Owens and Baker (2015) found informational support was that most frequently offered by group members. It has also been shown that network (Loane and D'Alessandro 2013) and esteem support (Fukkink 2011) are as prevalent or more so than emotional or informational support.

In an effort to examine the prevalence of different types of social support messages on health-related online support groups and to gain an understanding of why and when specific types of support messages were more common, Rains, Peterson and Wright (2015) conducted a meta-analytic review of content analyses examining support messages from 41 health-related online support groups. This covered 31 conditions including attention deficit disorder (ADD), cancer, diabetes, epilepsy, fibromyalgia, HIV/AIDS, irritable bowel disease (lBD) and obesity. Using the optimal matching model as a framework (Cutrona 1990, Cutrona and Russell 1990), 5 categories of support from the Cutrona and Suhr Social Support Behaviour Code (SSBC) coding scheme (1992) were grouped into two broad categories based on research regarding coping styles (Lazarus and Folkman 1984). These were action-facilitating types of support which encompasses informational and tangible support, designed to foster behaviour to mitigate a stressor, and nurturant support, which encompasses emotional, network and esteem support, designed to help people cope with the emotional outcome of a stressor. In the original model four dimensions - desirability, controllability, life domain and duration of consequences characterize stressors and make action-facilitating and nurturant support messages more or less beneficial (Cutrona 1990, Cutrona and Russell 1990). Rains, Peterson and Wright (2015) used 5 optimal matching variables tailored to the context of health to evaluate the dimensions of stressors - loss, stigma, controllability, duration and personal relationships. In line with the dimensions identified by Cutrona (1990) desirability was assessed by considering the potential for loss (i.e. death) and controllability was evaluated by considering to what degree people could take action to affect their situation. Duration was assessed by the degree to which the illness or condition is chronic/long term or acute/short term and the effects of that. Life domain was evaluated by considering the effect the condition had on personal relationships and stigma was assessed by considering how likely having a certain condition would be viewed as a stigma.

The authors found informational and emotional support messages to be those most prevalent in the communities identified, with esteem and network support messages appearing less frequently. There were no differences in the prevalence of informational or emotional support or in the prevalence of esteem and network support, and tangible support messages were those posted least frequently. This meta-analysis offers evidence to support the notion of online communication as a coping resource for people with a chronic illness and their carers (Tanis 2008, Wright et al 2011). The presence of informational and emotional support messages would indicate obtaining guidance and providing comfort are two primary functions, both associated with problem and emotion-focused forms of coping (Carver et al 1989). Informational support such as advice from other members about how to deal with your child’s hypoglycaemic episodes help foster problem focused coping (Merkel and Wright 2012) where parents can take action to avoid a stressor.

Emotional support such as messages from other members with a similar condition or illness has been shown to help people manage the negative effects associated with a stressor, and a sense of similarity that can extend to shared experiences helps reinforce this (Tanis 2008). Rains et al (2015) also noted that belonging to a health-related online support community was beneficial in that it provided access to a larger network of weak ties than available offline (Wright and Miller 2010). Haas et al (2011) proposed that through sustained participation in online support groups it is possible to transform a weak tie support network into a strong tie network. However, the authors note there are limits to some online support resources and unlike offline weak ties where people may ask others for tangible help, such as help collecting and delivering prescriptions, their results show support like this is limited and not typical online (Rains et al 2015).

Using the optimal matching model to assess when and why different types of support were more or less prevalent in online support groups, Rains et al (2015) found that the particular type of support message, be it emotional, informational, tangible, esteem or network varied based on several stressor dimensions that were applicable to the illness. Nurturant forms of support were shown to be more common in those reports that addressed health conditions with a greater potential for a terminal outcome, for example, cancer (Love et al 2012), HIV/Aids (Mo and Coulson 2008) and motor neurone disease (Loane and D'Alessandro 2013). The reasoning behind this was consistent with socio-emotional selectivity theory (Carstensen 1995, Lockenhoff and Carstensen 2004). This proposes if people are coping with a potentially life-limiting condition they should be concerned with regulating their emotions, and the results showed that esteem, emotional and network support messages were more prevalent in this case.

With regards to chronic conditions where the prognosis is less finite, socio-emotional selectivity theory envisages that obtaining information is a strong motivation. The results were consistent with this with both types of action facilitating support more prevalent among the studies that described chronic conditions such as such as diabetes (Robinson et al 2011), depression (Keating 2013) or eating disorders (Tong et al 2013). An interesting finding regarding the controllability of the stressor was that informational support was not more frequently noted among the studies that identified health conditions deemed to be more controllable, for example, conditions that rely heavily on a regular long term drug regime to manage the condition, such as diabetes. This may be due to the fact that many health conditions that develop are uncontrollable in the first instance.

Whilst stigma was not identified as a dimension of stressors in the original optimal matching model, it is a highly relevant construct that plays an important role in certain conditions such as HIV/AIDS, and online support has been seen as critical for those who perceive stigma due to their condition (Mo and Coulson 2013). Indeed, stigma has been reported as being experienced by individuals with type 1 diabetes and has led to people being labelled and devalued in certain societies. Difficulties in finding a spouse and punitive regulations regarding university admission and government employment have been levied against people with diabetes in China, forcing many to hide their condition to their detriment (Jaacks et al 2015). Less extreme, but nevertheless pertinent examples have been noted by researchers looking at features of online health communities for adolescents with type 1 diabetes (Ho, O'Connor and Mulvaney 2014). As health-related stigma has been shown to have implications for one's sense of self (Scambler 2009), it could be reasoned that encouraging other people's self-concept takes on a more significant role in online communities that cater to more stigmatised health conditions.

3.8.2 Self-Disclosure

A sense of anonymity, lack of visual cues and identifying information within online support groups can facilitate the perception of similarity, leading to people disclosing personal information (Nguyen, Bin and Campbell 2012). Self-disclosure in online support groups has been defined as posting messages which reveal personal information, thoughts and feelings to other members of the online community (Derlega et al 1993, Salem, Bogat and Reid 1997). This has been shown to be a common category of communication (Winzelberg 1997, Pfeil et al 2009), with higher levels of disclosure reported in comparison to face-to-face settings (Barak and Gluck-Ofri 2007). Wang, Kraut and Levine (2015) analysed a large corpus of data from an online cancer support group to examine the relationships between the 'conversational moves' members made when they started a new thread and the amount and type of support they received in response to them. Consistent with previous research the authors reported self-disclosure was effective in stimulating emotional support from other members, whilst posts asking questions rather than disclosing personal information or experiences received responses providing informational support.

In a related study, Lewallen et al (2014) identified linguistic markers of emotional expression and pronoun use in an online cancer support group.

Message topics were identified using qualitative analysis and it was found that 51% of the message content was related to self-disclosure and this was associated with the greater likelihood of a reply. The authors found that messages with a higher word count were also more likely to receive a reply, with messages of self-disclosure having the highest word count. This suggests that other group members are more likely to respond to longer messages from members willing to share details of themselves, which in turn may demonstrate a greater investment in the group. Messages about positive emotions received the least responses, suggesting members were more likely to reply to messages that contained less positive emotions. Lewallen et al (2014) framed this within the context of altruism, whereby members respond to a message when they perceive a greater need for support (Vilhauer 2009). Members may be less inclined to reply to messages that have a more positive tone, as they believe the member to be coping and in less need of support.

As well as empathy and understanding, a sense of commonality from other members encouraged people with Parkinson's disease to disclose personal information (Attard and Coulson 2012). Whilst members of online support groups may only identify with others by way of sharing certain health characteristics or experiences associated with a disease, they are able to share the most sensitive personal information and reveal intense emotions online (Barak and Gluck-Ofri 2007). Higher levels of emotional disclosure have been shown to increase the reciprocity between group members, with people more likely to respond to posts (Lewallen et al 2014), and this serves to increase the viewers perceived similarity with the poster (Malloch and Zhang 2019). Shim, Cappella and Ham (2011) noted that insightful and emotional self-disclosure in online support groups for women with breast cancer led to greater improvements in health self-efficacy, functional well-being and emotional well-being, which was mediated by lowered breast cancer concerns.

Whilst the focus of research on self-disclosure has predominantly been on the prevalence and positive impact on participant’s emotional and functional well-being (Barak and Gluck-Ofri 2007, Shim, Cappella and Han 2011), self-disclosure has been shown to be particularly beneficial when new members join an online support group. Sharing details about their health condition and personal experiences may help them become integrated with the group, leading to them receiving reciprocal emotional support because of sharing details that other group members can empathise with. Consistent with Yalom's Universality principle (2005), Lewallen et al (2014) suggests that those running online support groups, the administrators or moderators, should inform participants how to introduce themselves to the group by means of a more detailed and personal introductory message to foster greater group cohesion and maximise the possibility of altruistic and empathetic responses. However, there is limited research surrounding how people introduce themselves online in health support groups, and self-disclosure is by its very nature dependent on how individuals choose to interact in online support groups. This may be influenced by a number of variables, including the illness or condition, age or gender of the individual, and even their personality. As a caveat, higher incidence of online self-disclosure does not necessarily equate to the quality or depth of information being shared, rather it denotes a higher quantity of information (Attrill and Jalil 2011).

3.9 Psychosocial outcomes of participating in online support groups

Research examining health outcomes and the efficacy of participating in health-related online support groups has been shown to be limited. An early systematic review carried out by Eysenbach and colleagues in 2004 examined the social and health outcomes of online support groups used to discuss health-related issues, including depression, weight loss, eating disorders and diabetes control. The majority of the studies reviewed were carried out as part of other complex interventions by health professionals, with only six evaluating 'pure' peer-to-peer communities. Small samples sizes were noted throughout the studies and a lack of comparison groups, making it problematic to evaluate the efficacy of health benefits of online support groups. Similarly, a Cochrane review of randomised controlled trials (RCT's) conducted to assess the effects of online support groups on the emotional distress, anxiety, depression and quality of life (QoL) of women with breast cancer reported only 2 peer-to-peer studies, with small sample sizes of 30 and 78.

Whilst randomised controlled trials have long been viewed as the 'gold standard' in evidence based medicine, often lauded as the most scientific and rigorous design, it has been put forward that study design should be appropriate for the research question and take into account the population involved in the study. Grossman and Mackenzie (2005) highlighted that whilst some evidence-based medicine advocates exhort that public health interventions should be evaluated in the same way as pharmacological interventions, this is an oversimplification and generalisation, often not possible nor appropriate. The fluctuating nature of online support groups can make designing and conducting randomised controlled trials challenging for researchers. There can be a transient element to membership, with people joining and leaving the group at different times (Lieberman and Goldstein 2005). Studies have shown that large numbers of members leave an online support group before they obtain any benefit from other members (Resnick et al 2010, Yang, Kraut and Levine 2017). This can affect the trial sample size, and underpowered randomised controlled trials that describe comparative outcomes without significance are arguably of questionable benefit (Heneghan, Goldacre and Mahtani 2017). Whilst outcome studies investigating online support group efficacy remain somewhat problematic, a recent study presents a randomised control trial protocol for peer-to-peer support in the self-management of depression and anxiety (Kaylor-Hughes et al., 2017). The described protocol enables the measurement of a number of primary and secondary outcome measures, such as well-being, anxiety, social support and medical outcomes.

Despite the limited evidence for the physical health benefits of participating in online support groups, there is an expanding body of research that has demonstrated positive psychosocial outcomes and therapeutic benefits for people with a range of chronic illnesses, and their carers or parents.

3.9.1 Helper-therapy principle

The helper-therapy principle proposes that people gain specific benefits as a consequence of helping others (Reissman 1965), and this can be described as mirroring the possible benefits of receiving social support. Helping others in face-to-face support groups has been identified as therapeutic (Pagano et al 2010) and the helper-therapy principle asserts that helping others can enhance psychological and physical health of the helper (Post 2007). It has also been applied to health-related online support groups where members may feel an increased sense of self-efficacy and self-esteem through the process of helping others (Shaw et al 2008). Whilst people have been shown to join online support groups predominantly to find information and get support there is evidence of the helper-therapy principle when posted messages have been analysed (Batenburg and Das 2014, Blank et al 2010). van Uden-Kraan et al (2008) reported that members from breast cancer, arthritis and fibromyalgia online support groups stated one of the reasons for participating on forums was to help other members. Coulson and Shaw (2013) found evidence of the helper-therapy principle when examining the views and experiences of moderators across a range of online support groups. Moderators gained a sense of gratification from helping others and this behaviour was deemed an important mechanism for maintaining a productive online community. Armstrong, Koteyko and Powell (2012) found limited evidence of members helping other members on a diabetes forum, but found they were keen to demonstrate their own contribution in assisting others.

Conversely, Lepore et al (2014) carried out a randomised control trial to test the mental health benefits of women with breast cancer providing support to others on either a standard or enhanced prosocial Internet support group.

Symptoms of depression and anxiety were the primary and secondary outcomes. Both groups took part in 6 facilitated online weekly chats and had access to an asynchronous board to post messages, with participants allocated to the enhanced support group receiving written tips on how to recognise and respond to others needs for support. Arguably the first trial to test the psychological benefits of increasing helping behaviours, the authors found that the participants in the enhanced group showed more supportive behaviours towards other members and posted more messages that were other-focused and fewer that were self-focused. At the end of the trial, participants in the enhanced group showed a higher level of depression and anxiety symptoms in comparison to the standard group. Whilst the tips from the research team were shown to successfully manipulate supportive behaviours, this may have caused the participants to supress expressing their needs on the board, which led to them not being addressed by the group. These findings show that for women with breast cancer, helping others may not be beneficial as a way of improving psychological outcomes. This is at odds with the helper-theory principle, and the authors posited that previous studies have used cross-sectional correlational data and rarely included clinical populations. A further consideration is that helping others online may only be advantageous when it is not a burden or does not inhibit other therapeutic processes (Post 2007).

3.9.2 Enhanced self-efficacy and empowerment

Health-related online support groups afford individuals affected by chronic conditions the opportunity to access a collective pool of information, advice and social support from similar others, potentially facing similar challenges (Baum 2004, Brady, Segar and Sanders 2017, Kirk and Milnes 2016, Mo and Coulson 2012). Exchanging information and sharing lived experiences within the online support group can provide an understanding and social support that other friends, family members and healthcare professionals may not possess (Mo and Coulson 2014, Nicholas, Gutwin and Paterson 2013, Stewart et al 2011). As a consequence of this, online support group use can increase an individual’s ability to better cope with the condition or disease, and improve psychological well-being through enhancement of self-efficacy.

A key concept from social cognitive theory (Bandura 1997), self-efficacy is a personal resource that refers to the belief in one's ability to cope with stressful or challenging demands. In accordance with social cognitive theory (Benight and Bandura 2004), individuals in receipt of social support from health-related online support groups are likely to hold stronger self-efficacy beliefs. Consequently, this may increase the extent to which they are able to manage their own health care, affecting health outcomes (Lorig et al 2008, Magnezi, Bergman and Grosberg 2014, Willis 2016). This is particularly pertinent for chronic conditions such as diabetes where self-efficacy has been shown to be positively linked with successful diabetes self-management behaviours and improved health outcomes (Rasmussen, Dunning and O'Connell 2007).

Similarly, for carers co-managing chronic conditions participating in online support groups, self-efficacy is an important predictor of positive psychosocial outcomes. Robust evidence of this was demonstrated in a meta-analysis carried out by Parker Oliver and colleagues (2017) investigating the effect of online support groups for family caregivers of adult patients with chronic health conditions, including cancer, stroke, and dementia. Likewise, while parents co-managing their child’s diabetes needs have described increased levels of parental anxiety and depression (Streisand et al 2008), and reduced self-efficacy (Mitchell et al 2009) that may affect the quality of care they provide (Helgeson et al 2012), Merkel and Wright (2012) found parents who received social support from other parents in an online diabetes support group reported enhanced self-efficacy. In turn, the improvement in parents’ belief about their ability to manage their child’s diabetes care was found to be positively related to better coping. An important outcome, the amount of self-efficacy held has been shown to not only impact on levels of self-confidence and perseverance, but also the amount of anxiety an individual brings into the situation (Resnick 2004); with heightened self-efficacy helping to improve and maintain parents psychological well-being (Thorsteinsson, Loi and Rayner 2017, Swallow et al 2014). This aspect of online support group usage and participation along with the associated outcomes patients and carers affected by chronic health conditions testify to has been considered to facilitate a sense of empowerment for individuals (Barak et al 2008).

A complex concept due to the ambiguity around a clear and coherent definition and operationalisation (Boveldt et al 2014), the term empowerment may be considered as a multifaceted concept that can operate at the community, group or individual level (Zimmerman 1995). At the individual level, empowerment is a process whereby individuals experience an increase in feelings of self-efficacy, control or personal competence. Group empowerment is as a consequence of individuals coming together to collaboratively share knowledge, while community empowerment describes social or political activities individuals or groups participate in (Roberts 1999). Empowerment can therefore be considered as two different psychosocial phenomena, as an empowerment process or an outcome (Perkins and Zimmerman 1995, Rappaport 1987), enabling people to gain mastery over decisions and actions that affect their lives (Speer 2000). Psychological empowerment in the context of health care relates to peoples' strategies, abilities and actions that enable them to successfully manage their illness or condition (Toofany 2006). In this respect, with regards to health-related online support groups, empowerment may be viewed as an outcome of interpersonal and collective social action. Participants within these groups are able to receive action-facilitating types of support, i.e. informational and emotional support, which can then enable them to engage and facilitate in the empowerment of others. From this perspective, empowerment is a dynamic and relational process (Shearer 2009).

A number of studies have explored the concept and logics of empowerment within health-related online support groups (Barak, Boniel-Nissim and Suler

2008, Lemire, Sicotte and Paré 2008). Qualitative research carried out by van Uden-Kraan and colleagues (2008), examined if, and in what ways, members of online support groups for breast cancer, arthritis and fibromyalgia felt empowered through participation. The authors distinguished between empowering processes (processes that transpire during participation) and empowering outcomes (changes that occur as a result of participating). Exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others and amusement were all identified as empowering processes. Participants also reported being better informed, enhanced social well-being, improved confidence in their relationship with their health care team, greater acceptance of their disease, increased optimism and feelings of control, enhanced self-esteem and social wellbeing and collective action. These empowering effects were evident in a subsequent larger quantitative study by van Uden-Kraan et al (2009), with 'being better informed' and 'exchanging information' shown to be the empowering outcome and process occurring most frequently/to the strongest degree. Previous research indicates that the empowerment outcome 'being better informed' is as a consequence of participants having a better understanding and being better informed about their health condition as a result of receiving peer support (Buchanan and Coulson 2007, Campbell, Phaneuf, and Deane 2004). It is to be expected that the process of ‘exchanging information’ within online support groups would foster empowerment as group members are able to offer lived experiential advice in contrast to health professionals where the emphasis is on more factual information (van Uden-Kraan et al 2008b). This should not imply it is necessary to use these two types of information in isolation of each other; indeed, it may be beneficial that they are used concurrently.

The research by van Uden-Kraan et al (2008) examining empowering processes and outcomes and the resultant questionnaire developed by the authors has been employed by successive researchers across a variety of health conditions, with the original findings replicated to a greater or lesser degree. Health conditions considered have included cancer, HIV/AIDS, infertility and eating disorders (Aardoom et al 2014, Bartlett and Coulson 2011, Campbell, Coulson and Buchanan 2013, Mo and Coulson 2010, Malik and Coulson 2010), and the van Uden-Kraan et al (2008) questionnaire continues to inform research regarding empowerment in online communities. To date no study has used this to consider the empowerment processes and outcome of online support groups for people with and affected by type 1 diabetes. However, a related study by van Berkel, Lambooij and Hegger (2015) focusing on patients with diabetes, amyotrphic lateral sclerosis (ALS) and attention deficit hyperactivity disorder (ADHD) investigated whether discussions about medication on online message boards could contribute to patient empowerment and result in improved medication adherence. Low adherence to prescribed treatment has been estimated to be as low as 50% for some conditions (EDQM 2012).

For people with a chronic condition that requires timed, well-controlled life-long medication, health knowledge and empowerment have both been shown to have a significant effect on self-management (Camerini, Schultz and Nakamoto 2012). Taking an active role in managing their health can increase people's self-efficacy, shown to contribute to more successful self-management (Armstrong and Powell 2009). In the van Berkel et al (2015) study over 5000 posts related to the conditions from associated online message boards were coded using deductive thematic analysis and the categories related to empowerment drawn from the research of van Uden-Kraan et al (2008) were used to guide the coding. From this, the following empowerment process categories were identified: providing information, requesting information, sharing personal experiences, exchanging empathy or support, gratitude and comparison with other members. The results showed patient empowerment processes were identified in posts from all conditions. Whilst there was some slight variation in the frequency, there was consistency in the order of the results, with the two most prominent processes being providing information and sharing personal experiences. This was consistent with previous research that has shown the benefits of sharing experiences and empathy (Sillence 2010), with those who offer higher levels of support to others shown to experience more positive outcomes (Kim et al 2012).

The authors also looked at the quality of the information in the messages for each of the three conditions to evaluate if this could contribute to an individual's self-efficacy with regard to their medication. They observed the information shared was generally correct and if misinformation was posted, other members would draw attention to this. Whilst the topics under discussion did not necessarily promote empowerment, it has been suggested that disingenuous information could have a disempowering effect if it was accepted and used (Schulz and Nakamoto 2011, Mo and Coulson 2014). However, there is evidence that shows online support groups monitor and challenge misleading information (Esquivel, Meric-Bernstam, and Bernstam 2006), often overseen and implemented by group moderators (Smedley and Coulson 2016).

While the literature corroborates the empowering processes and outcomes initially proposed by van Uden-Kraan et al (2008), and it appears that health-related online support groups instil participants with feelings of empowerment, it has been suggested that people will experience empowerment in different ways and this is true for the meanings it will have for them as well (Broom 2005).

3.10 Summary

Existing research regarding health-related online support groups highlights the important role they play for people with a variety of conditions. They have been shown to provide a sense of community with unique characteristics where people can search for information, share information and disclose personal experiences. Additionally, people can offer and receive support and as a consequence of using online support groups may feel more empowered. As a result, people may experience physical and psychological benefits that enable them to better understand and manage their condition and improve their quality of life. However, the research surrounding type 1 diabetes and online support group use is scarce and has historically focused on online interventions, more often concerned with improving glycaemic control.

Few studies have investigated if and how diabetes online support groups may provide a venue and community for parents of adolescents with type 1 diabetes that facilitates the exchange of social support. Furthermore, whilst various psychosocial benefits of group membership have been reported for patients, caregivers and parents from studies exploring other condition specific online support groups, little is known about the online experiences, and any psychosocial consequences thereof, for these parents affected by diabetes.

It is plausible that parents of a child with type 1 diabetes, a life changing and potentially life limiting chronic condition, will have different concerns compared to other people managing other conditions or diseases. These concerns may increase or change dependent on their child’s developmental stage, for example, as they enter adolescence and become more responsible for managing their diabetes. In response, parents' requirements for social support can fluctuate or intensify. The potential advantages of health-related online support groups demonstrated in previous research could benefit parents co-managing their child's diabetes. Having access to an online support group populated by others who share similar experiences may lead to homophilic relationships developing. Research considering how advantageous or otherwise this may be for parents of adolescents with type 1 diabetes is scarce. The current research aims to address this gap in the literature by using a mixed-methods approach to conduct three complementary empirical studies to investigate how and why this cohort uses diabetes online support groups, and to see if group membership affords any psychosocial benefits. Addressing this under-researched area will add to the knowledge base of the role health-related online support groups have for parents with a child affected by a chronic condition.

Chapter 4: Research methodology and methods

4.1 Introduction

While the literature reviewed in Chapters 2 and 3 of this thesis identified potential benefits of health-related online support group use, it was ascertained a gap exists in the current body of research examining online support group use by parents of adolescents with type 1 diabetes. This chapter presents a rationale for conducting research with this cohort. It provides details of the methodological approach and methods used to fulfil the overarching aims of the research. The choice of a mixed methods approach and an explanation of the philosophical principles underpinning this decision are discussed, including the challenges this presents. The methodology chosen for the each of the 3 empirical studies is examined before the ethical implications of online research are considered.

4.2 Rationale for using mixed methods

4.2.1 The aims of the study

The Internet has become an increasingly popular and accessible source of health-related information, advice and peer support augmented by the use of health-related online support groups. Offering a sense of anonymity, and a greater accessibility to similar others due to the lack of spatial or temporal constraints associated with face-to-face groups, individuals feel able to discuss potentially sensitive topics in perceived safety without fear of embarrassment or reprisal (Buchanan and Coulson 2007). As discussed in Chapter 3, the use of online support groups has been shown in the psychology literature to have therapeutic benefits congruent with face-to-face support groups. However, the literature regarding the use of online support groups for people affected with and by type 1 diabetes is limited, and is often included as part of research that considers other chronic conditions as well. Historically, the propensity of studies dedicated to type 1 diabetes has mainly focused on Internet based support interventions with an emphasis on measuring and improving glycaemic control and self-management. Little is known about the psychological effects of using health-related diabetes specific online support groups, the possible therapeutic benefits or the potential limitations. Therefore, the aims of the studies within this thesis are:

- To explore how and why parents of adolescents with type 1 diabetes use health-related online support groups during the transition from paediatric to adult diabetes services.
- To gain an understanding of the motivations for using these online support groups.
- To consider if using health-related online support groups may empower individuals affected by type 1 diabetes and the consequences of this.
- To consider the impact health-related online support groups has on parental psychological well-being during this period of transition.

In order to best meet these research aims it is necessary to identify an appropriate research method. Deciding which method(s) to adopt should be governed by, and complement the subject under consideration. The most appropriate method should be able to demonstrate its suitability to address the research question(s) with clarity and integrity, whilst taking into account practical implications that may have a bearing on the research (Hine 2008). Research methods may be distinguished by the sources of information, how this is sampled and the tools used for data collection. Additionally, research methods are distinguished by the type of data that are collected. This can be quantitative data, qualitative data or a combination of the two. Combining qualitative and quantitative research methods is referred to as mixed methods research (Dures et al 2011), and this involves philosophical assumptions as well as technical methods of enquiry.

Bishop (2015) contends that some researchers may focus exclusively on the technical challenges of mixed methods research, i.e. quantitative methods are viewed as techniques for obtaining and analysing numerical date, and likewise, qualitative methods are simply techniques for obtaining and analysing non-numerical data. If researchers adopt this approach there is a danger that this purely technical focus promotes a superficial and inadequate approach to mixed methods research, encouraging uncritical, unreflexive practices, and ultimately poor quality research (Wiggins 2011). Online support has been shown to be a complex phenomenon (LaCoursiere 2001), and researching this requires a more comprehensive approach that goes beyond a singular qualitative or quantitative technical process; as neither approach would be sufficient individually to explore it in such depth. A mixed methods approach employing qualitative and quantitative methods would better address this level of complexity. Murphy et al (2014) propose that mixed methods research, if carried out correctly, may have added benefits and values that might be considered as a third methodological paradigm.

4.2.2 Philosophical debates over mixed methods research

Combining qualitative and quantitative research methods has been subject to much debate as they represent alternative research paradigms and philosophical principles. Guba and Lincoln (1994) state that the basic beliefs that define a particular research paradigm may be summarised by the responses given to three fundamental questions:

- The ontological question - what is the form and nature of reality?
- The epistemological question - what is the basic belief about knowledge?
- The methodological question - how can the researcher go about finding out whatever they believe can be known?

Quantitative approaches to research are traditionally aligned with positivist epistemologies (Sale, Lohfeld and Brazil 2002) and characterised by empirical research. This paradigm adopts the ontological position of an objective reality existing independently of human perception, and that ascribes to the notion of there being one 'truth.’ Epistemologically, the object of inquiry and researcher are separate entities, and the researcher does not have any influence on that object and vice versa. Examples of research methods compatible with this paradigm would include questionnaires with predetermined response categories. In comparison, qualitative approaches are associated with constructionist or interpretive epistemologies (Johnson and Onwuegbuzie 2004, Yardley and Bishop 2008). Ontologically, this paradigm assumes multiple truths and realities exist as opposed to objective truth or reality. There exists a relativist epistemology where the researcher and participant co-create understandings, where the researcher is part of the context of the phenomenon that is being investigated. Each bringing their personal experiences and perspectives to the research (Johnson and Onwuegbuzie 2004, Sale, Lohfeld and Brazil 2002, Speziale, Streubert and Carpenter 2011).

As well as ontological and epistemological differences between the two paradigms, further differences are apparent regarding the type of logic invoked (whether deductive or inductive), the purpose of the research (be it confirmatory or exploratory) and the types of research question that may be appropriately considered. Differences also exist between the types of data required (either narrative or numerical), participant sampling (purposive or probability) and the method chosen to analyse data (statistical or thematic) (Teddlie and Tashakkori 2011). These have led purists to claim that quantitative and qualitative approaches are incompatible as 'the one (paradigm) precludes the other just as surely as belief in a round world preclude belief in a flat one' (Guba 1987, p.31). This is also seen to be the case with regards to combining research methods, as they would postulate methods are irrevocably aligned to a single paradigm (Teddlie and Tashakkori 2011). There are limitations that should be taken into account and acknowledged when choosing to use a single research method approach. A qualitative methodology is more likely to be affected by researcher bias, lack of concern with generalizability of findings and low reliability (Al-Hamdan and Anthony 2010). In comparison, quantitative methods are limited in their ability to adequately describe in depth people’s experiences. They lack the ability to look at the subtleties of interplay amongst phenomena that shape choice or individual behaviour, and for this qualitative research methods would be better suited to investigate behaviour through the perceptions, understandings and beliefs that motivate individuals. Nevertheless, it has been argued that quantitative and qualitative approaches can be combined and there is as much diversity within the paradigms as exists between them (Hammersley 1996).

4.2.3 A pragmatist approach

Advocates of a mixed methodology approach suggest that the two paradigms that have historically dominated research, qualitative and quantitative, may not be the only paradigms and suggest pragmatism offers an increasingly popular approach to the philosophical challenges of mixed methods research (Cornish and Gillespie 2009, Tashakkori and Teddlie 2011, Yardley and Bishop 2008). Adopting a pragmatist epistemology involves drawing on pragmatist philosophers such as Charles Sanders Peirce, William James, John Dewey and George Herbert Mead to develop a more sophisticated approach to mixed methods research (Yardley and Bishop 2008). Pragmatics assert, *'all human enquiry involves imagination and interpretation, intentions and values, but must also necessarily be grounded in empirical, embodied experience'* (Yardley and Bishop 2008, p.335).

Practical consequences are viewed by pragmatists as essential components of meaning and truth. Theories are 'true' to differing degrees, dependent on how well they 'work' at that moment in terms of applicability and feasibility. In this sense, truth and meaning are considered provisional, tentative and conditional (Dures et al 2011). Creswell (2009) proposed several ways in which pragmatism provides a basis for the following knowledge claims, and how this corresponds with a mixed methods approach:

1. Pragmatism is not committed to any one system of philosophy and reality, allowing researchers to draw from quantitative and qualitative assumptions during their research.

2. Individual researchers are not restricted in their choice of methods, techniques and procedures, but free to choose what best meets their needs and purposes.
3. Pragmatists do not view the world as an absolute unity, and similarly, mixed methods researchers consider multiple approaches (e.g. qualitative or quantitative) to collecting and analysing data.
4. Truth is what works at the time. It is not based in a strict dualism between the mind and reality independent of the mind. In mixed methods, researchers use both quantitative and qualitative data because they provide the best understanding of the research problem.
5. Pragmatist researchers consider the 'what' and 'how' to research in terms of its intended consequences, and what they hope to achieve. Mixed method researchers need to provide a rationale for why mixing qualitative and quantitative data are required.
6. Pragmatists agree that research occurs in context, be that social, historical or political. Therefore, mixed methods studies may provide a reflexive perspective of social justice and political aims.

The combination of a mixed methods approach and a pragmatist paradigm enables researchers to choose the most suitable methods to meet the needs of the research. As a caveat, Yardley and Bishop (2008) note that two different kinds of research must be combined in such a way as to preserve their integrity. To address this, Sale, Lohfeld and Brazil (2002) propose using qualitative and quantitative methods for 'complementary purposes' as 'each method studies different phenomena' (Sale, Lohfeld and Brazil, p.50). In this way, the different methods focus on different aspects of the subject area under investigation, and may elaborate, clarify or enhance the one method with the other.

4.3 The mixed methods research design

In order to fulfil the research aims detailed in section 4.2.1 an exploratory sequential mixed method design will be used employing quantitative and qualitative methods, and incorporating pragmatist philosophies. Notions of complementarity will be used as a rationale for combining research methods, as proposed by Sale, Lohfeld and Brazil (2002). The research consists of three stages. Stage 1 is a predominantly quantitative phase, which consists of an online survey using a questionnaire to obtain quantitative data (see Chapter 5). This will include general demographic information regarding age, sex, education, as well as questions about Internet use and habits relating to diabetes and health. Pre-existing questionnaires will be incorporated into the survey. This includes the Revised Illness Perception Questionnaire for Diabetes (IPQ-R Diabetes) (Moss-Morris et al 2002), the Parent Diabetes Distress Scale (DDS-P) (Hessler et al 2012) and the online questionnaire devised by van Uden-Kraan et al (2009) which explores to what extent people feel empowered by their participation in online support groups. The survey also contains a number of open-ended questions to allow participants to provide further information in their own words. This is designed to add a further personal dimension to the data that reflects the uniqueness of each participant and their experiences. Analysis of Study 1 data is then used to inform an interview schedule for Study 2 (see Chapter 6), which is the qualitative phase of the research and consists of semi-structured telephone interviews. Study 3 (see Chapter 7) is a thematic analysis of messages posted over a period of 5 months on a type 1 diabetes online support group. The combination of quantitative and qualitative methods to explore different aspects of the role health-related online support groups have for parents affected by type 1 diabetes, will provide a better more complementary understanding of the phenomenon than either approach alone (Creswell and Plano Clark 2011).

The next part of this chapter will identify the individual methodologies chosen for the three studies: an online survey, semi-structured interviews and thematic analysis of messages posted on a diabetes online support group.

4.3.1 Online survey

The following section will discuss the choice of an online survey using questionnaires as the analytical method for Study 1. The strengths and limitations of this method will be addressed.

Surveys are defined as *'systematic methods for determining how a sample of participants respond to a set of standard questions attempting to assess their feelings, attitudes, beliefs or knowledge at one or more times'* (Marks et al 2015, p.107). This is the process of gathering data and may include using a variety of questionnaires, different types of interviews or a combination of the two. Questionnaire based research has been widely used in Health Psychology and has traditionally been delivered by the pencil and paper method (Knapp and Kirk 2002). However, the development of the Internet and its ubiquitous nature makes it an advantageous tool for researchers (Gosling and Mason 2015). There are a number of ways to electronically distribute questionnaires via the Internet. The questionnaire may be sent to potential participants in an email message, either as an attachment or within the body of the email itself, or with a hyperlink to a web-based survey. Alternatively, a general request for participants may be posted as a message in an online community, with a hyperlink to the survey. Online research is a logical methodological option to obtain data appertaining to online support groups, and can be used to investigate the experiences of people who use them, by amassing quantitative and or qualitative information. Study 1 uses a web-based online survey that gathers demographic and quantitative data by using pre-existing standardised questionnaires (detailed in section 4.3) with additional open-ended questions to obtain qualitative data.

4.3.1.1 Advantages and disadvantages of online surveys

There are a number of benefits to using online surveys that have been identified in comparison to the pencil and paper approach. Sills and Song (2002) contend that for conducting research with populations who are *'connected and technologically savvy'*, the cost, ease, speed of delivery and response, ease of data cleaning and analysis are indicative of the benefits of using the Internet as a delivery method for survey research (Sills and Sog 2002, p.28). The cost of conducting online surveys may be considerably cheaper than traditional postal questionnaires which require postage to be paid, and can produce quicker responses due to fact that information is electronically gathered immediately rather than researchers having to wait for postal questionnaires to be completed and returned (van Selm and Jankowski 2006). This is beneficial for researchers who are working to strict timescales and need to manage the time and financial resources available. There may be set-up costs associated with conducting research online and this can vary dependent on the computer equipment required, the software needed and the servers required to host the survey (Mann and Stewart 2000). Additional software may be required for analysis and researchers may require training in how to design and conduct online surveys. All these factors need to be taken into account and considered at the initial planning stage. However, before designing and undertaking online surveys, the researcher should be confident that this is the appropriate method for the topic and population under investigation (Naus, Philipp and Samsi 2009). It should also be taken into consideration that the increase in the adoption of online surveys as a research method may lead to 'survey fatigue' among certain populations (Witte 2009). This is when Internet users are repeatedly invited to take part in online surveys, and because of over-surveying, conversely, a decrease in response rates may occur (Van Mol 2017).

In the case of the current research, an online survey investigating parents' experiences of diabetes online support groups was deemed apposite, and posting a link to the online survey on each of the diabetes support groups identified was the most judicious way of contacting and recruiting potential participants. Obtaining the contact details of each member of an online support group and attempting to contact them directly is time-consuming, and if people do not update their contact details they may not be not contactable (Im and Chee 2012). They may also feel their privacy has been invaded if they receive emails from strangers or treat the email as spam and ignore it. Mann and Stewart (2000, p.73) noted that *'a stranger wanting to do academic research is sometimes seen as an unwelcome arbitrary intrusion.'* Moreover, membership numbers may run into the thousands and this makes an online survey a more cost effective and efficient way of recruiting participants. This can be beneficial for participants as well, as with an online survey they are able to choose a time and location that suits them to complete the survey (Birnbaum 2004). They can retain a sense of anonymity, a characteristic of online communities that has been shown to be valued (Coulson and Knibb 2007) and advantageous when dealing with sensitive information (Rains and Young 2009, Vilhauer 2014).

The benefits of anonymity can also extend to the researcher and may be instrumental in reducing demand characteristics (Hewson, Laurent and Vogel 1996), whereby participants behave in a certain way to please the researcher or tailor their responses to corroborate the experimental hypothesis (Nichols and Maner 2008). Research bias may also be reduced because of the anonymity afforded by the Internet, where previously the researcher may have been influenced by characteristics of the participant such as age, gender or ethnicity (Hewson et al 1996). This anonymity may have the effect of prohibiting a rapport developing between the researcher and participant (Hunt and McHale 2007), yet there is evidence to support the view that the anonymity of an online survey may elicit more candid responses compared to postal surveys (Bryman 2012). A study by Kays, Gathercoal and Buhrow (2012) compared a web-based survey of the National College Health assessment with a paper version of the same survey, completed by college students in the US. They found that web-based formats had better response rates for highly sensitive questions, particularly in the male students.

There are a number of challenges facing researchers who choose to use web-based surveys. It may be difficult to detect deception online, for example, if participants complete the same survey on more than one occasion, or complete it pretending to be someone else (Nosek, Banaji and Greenwald 2002), this can call into question the validity of the data. For web-based surveys there are limited strategies that researchers can employ to identify multiple responses from participants. Identifying the IP address and checking for duplicates has been suggested (Gosling et al 2004) but not all survey software has the capability to do this, and with regards to the current research two parents of the same child could use the same computer with the same IP address. Asking participants to provide an email address and cross referencing these to check for duplicates is another option (Wright 2005), but it should be noted that people may have multiple email addresses, or may wish to remain anonymous and not provide an email address.

Another challenge researchers face when using online surveys to investigate online support groups is that of the representativeness of the sample. Internet access is not equally distributed across the population (Office for National Statistics 2019), and as discussed in Chapter 3, varies by socio-demographic factors including age, gender, income and educational level. Consequently, recruiting participants via the Internet can produce restricted samples (Hunt and McHale 2005), also influenced by the way potential participants are made aware of the research. As previously discussed, there are a number of options researchers can use to contact members of an online support group to invite them to participate in research, namely a direct email to each member or by posting a message on the board giving details of the study and a hyperlink to the survey. Direct emails may be a logistically problematic approach; group administrators may not divulge the information, it may be out of date or the email misdirected or ignored. Making details of the research and invitation to participate visible on the online groups board means that people will see it when they access the group, including people who lurk or contribute to posts on a less frequent basis.

A possible weakness of this approach is that newer posts will move the original post further down the board, reducing its visibility. 'Bumping' the post by commenting on it will have the effect of re-positioning it further up the board and keeping it more visible, but researchers should be cautious about using this approach too often much as it may be deemed annoying or intrusive by other members. Another option is asking the group administrators or moderators to make the post a sticky. This means the post is stuck at the top of the board and they are more usually used for forum rules or announcements relevant to the group as a whole. Whilst this method keeps the post visible, there is no evidence to the efficacy of sticky posts, nor is there an accurate way to determine how many group members and potential participants have read messages, which makes establishing a sampling framework problematic (Wright 2005).

Hamilton and Bowers (2006, p.824) suggest *'like any other sampling plan, use of the Internet must make sense in relation to the research question and not be advocated based simply on ease and researcher accessibility.'* Similarly, Boydell et al (2014) advocate that researchers should articulate their rationale for choosing to recruit online and suggest that if this is not made explicit one could assume recruitment was driven by pragmatism. Following a review of the literature on health-related online support groups, and given the inclusion criteria and research aims of the current study, a purposive sampling strategy was the most appropriate to apply to this study (Ritchie, Lewis and Elam 2013). Obtaining access to diabetes online support groups, and posting details of a web-based online survey was reasoned to be an effective recruitment strategy.

4.3.2 Semi-structured Interviews

4.3.2 Semi-structured Interviews

The following section will outline the choice of semi-structured qualitative interviews as the data collection method for Study 2 (see Chapter 6) of the thesis. The benefits of this method will be considered as well as the options open to researchers for conducting semi-structured interviews.

Three types of interviews are primarily considered within social science qualitative research: structured, unstructured or semi-structured (Bryman 2012). Structured interviews involve strictly defined pre-prepared questions that are asked of a person or group concerning a particular research issue. From the researcher's or interviewer’s perspective, they remain neutral observers. There should be no prompting or improvisation in the questions and rapport with participants is kept to the minimum (Byrne 2012). In contrast, unstructured or open interviews offer a more relaxed and flexible approach. Conversational in style, the researcher will ask a question and then allow the participant to respond in whatever manner and depth they wish to (Bryman 2012). Interruptions or prompts are kept to a minimum, with the emphasis for the researcher on active listening. Finally, semi-structured interviews lie between these two extremes. Here the researcher may use an interview guide with open-ended questions to help direct the interview. This gives participants the opportunity to respond more freely in the way they discuss their thoughts and opinions, rather than being constrained by a direct closed question that requires a direct limited response (Hoffman 2007, Marks et al 2015). Furthermore, semi-structured interviews enable a more multi-directional interaction between the researcher and participant (Galletta 2012). While an interview guide provides a general structure, the researcher has the flexibility to respond to participants answers; starting a dialogue that could potentially generate further lines of enquiry and provide novel insights (Cridland et al 2015).

Typically, qualitative semi-structured interviews have been conducted face-to-face, with telephone interviews becoming an increasingly more commonplace alternative (Irvine, Drew and Sainsbury 2013, Mealer and Jones 2014, Opdenakker 2006). Advances in technology has meant other options are also available, for example, email exchanges, Skype or other audio-visual platforms (Janghorban, Roudsari and Taghipour 2014, O'Connor and Madge 2016). There are potential drawbacks if equipment or software is required which participants do not have access to, or want to use. The cost may be prohibitive for some, or they may not have the technical skills or time to install software and familiarise themselves with it (Ayling and Mewse 2009). While the benefits of face-to-face interviews have been well documented (Opdenakker 2006), with physical proximity advantageous in terms of identifying and responding to non-verbal cues such as body language and facial expressions (Nagy et al 2010), it requires a mutually convenient location which may be problematic. Addressing this, telephone interviews are a viable option that negates the need for interviewer and interviewee to be in same location. Interviews can be recorded for transcription later, which allows the researcher to concentrate on the interview, being sensitive to any paralinguistic cues that may indicate a problem, particularly if sensitive issues are being discussed (Mealer and Jones 2014, Musselwhite et al 2007).

In the case of the current research, semi-structured telephone interviews were considered the most suitable and pragmatic method for data collection. Interviews could take place at a time that was convenient for participants in a location of their choice. In contrast to a more prescriptive approach, semi-structured interviews would allow participants to discuss their experiences of diabetes online support groups and introduce their own personal thoughts and feelings during the interview process. A semi-structured interview schedule was designed following analysis of the results from the first empirical study, the online survey, taking into account the literature surrounding online support groups previously reviewed in Chapter 2 and Chapter 3 of this thesis, and the research aims identified earlier in this chapter.

4.3.3 Message posting analysis methodology

The following section will discuss the choice of analysing message posts as the method for the third study of the thesis (see Chapter 7). This study will analyse the thematic content of posts from a type 1 diabetes online support group to gain a further insight into the role they have for people affected by type 1 diabetes.

Researchers have become increasingly interested in investigating the implications of online communication for social support processes over the last twenty years (Rains, Peterson and Wright 2015, Wright et al 2011). Health-related online support groups can provide people with an additional or alternative form of social support. They are viewed as a convenient and accessible environment in which to obtain and share information and interact if desired with similar others (Coulson and Greenwood 2012, van Uden-Kraan et al 2009, Coulson, Buchanan and Aubeeluck 2007, Morris, Daluiski and Dy 2016, Lu et al 2011). Analysing the communication that takes place between members on online support groups has been shown to offer an insight into the nature of the interactions between members. This can provide valuable information about the utility and efficacy of online support groups for those actively participating across a variety of health conditions (Malik and Coulson 2010, van Uden-Kraan 2008, Perrone et al 2015, Ravert, Boren and Wiebke 2015). For that reason, an investigation of naturally occurring online conversations within a type 1 diabetes online support group was determined to be a meaningful qualitative method to employ for Study 3 of the current research. As part of a mixed method approach, Study 3 will provide additional insight into the role health-related online support groups have for parents affected by type 1 diabetes (Creswell and Plano Clark 2011). It will be used to explore further the characteristics of online social support, and will be beneficial to corroborate and expand upon the findings from the survey and interview data from Study 1 and Study 2, in keeping with the tenets of a mixed method approach.

There are a number of ways researchers have investigated the communicative processes within health-related online support groups. Thematic analysis is a qualitative analytic method. Described as *'a method for identifying, analysing and reporting patterns (themes) within data'* (Braun and Clarke 2006, p.79), it has been widely used within social science research. It has at times also been labelled 'thematic content analysis' (Green and Thorogood 2004) and referred to and treated as 'content analysis' (Meehan, Vermeer and Windsor 2000).

Whilst the terms thematic analysis and content analysis have sometimes been used interchangeably (Vaismoradi, Turunen and Bondas 2013) and there are similarities between the approaches, there are also differences. It is therefore judicious to briefly highlight the distinction between the two.

Content analysis is a general term for a number of different strategies used to analyse text (Powers and Knapp 2011). It provides a systematic coding and categorisation approach for exploring a textural dataset to identify patterns of words, frequency, their relationships and the structures of communication (Gbrich 2013); effectively, a quantitative analysis of qualitative data. Thematic analysis is a qualitative form of analysis which (minimally) summarises themes within the data set whilst attempting to explore meaning in more depth (Braun and Clarke 2006). Here prevalence is not considered as significant as with content analysis. Whilst there needs to be a number of recurrent instances in the data if something is to be considered a theme, it is more important that the theme is representative of something of analytic importance that addresses the aims of the research or research question (Braun and Clarke 2013).

4.3.3.1 Deductive and Inductive analysis

The application of content and thematic analysis is associated with two modalities, deductive and inductive. Deductive thematic or content analysis has been widely used in the area of online support group research. Researchers have favoured the Cutrona and Suhr (1992) social support framework or a commensurate coding scheme to examine the prevalence of informational, emotional, esteem, network and/or tangible support messages for a range of health conditions including Huntington’s disease, cancer, diabetes, amyotrophic lateral sclerosis (ALS) and complex regional pain (Coulson, Buchanan and Aubeeluck 2007, Coulson and Greenwood 2012, Robinson et al 2011, Loane and D’Alessandro 2013, Smedley et al 2015).

Some researchers have chosen an alternative to the deductive analytic approach, and have utilised a data driven inductive approach when analysing message posts from online support groups including Parkinson's disease, carers of people with dementia and adult children of parents suffering mental illness (e.g. Attard and Coulson 2012, McKechnie, Barker and Stott 2014, Widemalm and Hjärthag 2015). An inductive approach may be used in cases where there is limited research about the phenomenon under investigation and the coded categories are derived directly from the text, rather than identified by using pre-defined theoretical frameworks. This can be a beneficial approach in identifying issues or themes that may be specific to a specific or unusual health condition. It can provide rich data in contrast to a deductive approach, which is more relevant if the research aim is to test a previous theory in a different situation or compare categories at different periods (Elo and Kyngäs 2008).

Different inductive analytical approaches have been used to analyse the communication on health-related online support groups, including grounded theory (Haas et al 2011, Lawler and Kirakowski 2014), interpretative phenomenological analysis (IPA) (Graffigna, Libreri and Bosio 2012, Hadert and Rodham 2008) and inductive thematic analysis (Attard and Coulson 2012, Hanna and Gough 2016, Meade, Buchanan and Coulson 2017, Mo and Coulson 2014). Choosing to use a deductive or inductive approach should be directed by matching the specific research purpose to the appropriate analysis technique (Hsieh and Shannon 2005).

4.3.3.2 Advantages and disadvantages of message posting analysis

There are a number of potential advantages to analysing messages posted on health-related online support groups (Smedley and Coulson 2018). Firstly, the number of such groups and associated membership continues to grow, covering a wide and diverse range of health conditions, with many of the online groups deemed to be public, openly accessible groups (Eysenbach and Till 2001). This means that unlike closed groups, which require people to register before they can view the online content, anyone can access and search the group to read messages posted by other people. This can afford researchers access to a potentially abundant volume of expedient available data with relative ease and with minimal expenditure (Wilkinson and Thelwall 2011). This also includes gaining access to publicly displayed content that demonstrates the views and experiences of group members who may not wish to participate in more conventional research or are part of a hard-to-reach population (Seale et al 2010, Wilkerson et al 2014). However, some online support groups have moderators (Matzat and Rooks 2014) who act as 'gatekeepers' necessitating researchers obtain permission before they start to collect data. In private or closed online groups, researchers may first have to register to join the group or contact the group's moderators or administrators to request permission to collect data. This distinction between public and private groups and the rights of researchers to mine and analyse data from them raises some unique ethical considerations around informed consent, anonymity and confidentiality (Whitehead 2007). These will be addressed in more detail in a later part of this chapter.

Secondly, the communication that occurs between members as posted messages can offer researchers a unique insight into the purpose and dynamics of the online community, providing a rich source of naturally occurring qualitative data (Jowett 2015, Potter 2012). Analysis of the messages posted can highlight the needs and requirements of people living with a specific health condition, be that for informational or emotional support (Haik et al 2019, Love et al 2012, Rains, Peterson and Wright 2015). Furthermore, analysis can be carried out to explore details of group members' experiences, presented in their own words, and unexpurgated (Bond et al 2013).

Analysis of message postings may also serve as a historical timeline that can chart the development of the group. This is particularly true of long-established groups, although this does not preclude exploring the experiences of members on newer groups. Smedley et al (2015) examined the content of messages on a newly launched online complex regional pain syndrome discussion group to consider what kind of social support was available and how support processes become established. The authors found that the support processes began almost as soon as the group was launched, and this was congruent with behaviour found in face-to-face support groups when people meet for the first time and support others.

Another advantage of message posting analysis is that the researcher is not involved in the creation of data, therefore reducing some of the biases associated with more participatory research such as selection bias or social desirability (Jansen and Saint Onge 2015). Finally, analysis of posted messages may provide a way of obtaining data from groups that have been regarded as deviant, or oppositional subcultures where it may have been difficult or even dangerous for researchers to gain entry to the group (Chang and Bazarova 2016, Gavin, Rodham and Poyer 2008).

There are some weaknesses inherent with analysing message postings. It may not be possible to collect accurate sociodemographic information about group members due to the anonymous nature of member profiles. However, Kang (2017) noted that in an online support group for breast cancer online the more discursive anonymity individuals have on their profiles, i.e. using pseudonyms and no distinguishing names or characteristics, the greater the level of disclosure about themselves. Unfortunately, there is no way of finding out about the experiences of people who access online support groups but do not post any messages, known as lurkers, using this method (Edelmann 2013, van Uden-Kraan et al 2008). Nor is there an accurate way to calculate with certainty what percentage of group members contribute to online conversations. Fullwood et al (2019) argued that lurkers make up a substantial percentage of any online support group, citing estimates that range from 45.5% to 90% in some groups previously studied (Mason 1999, Nonnecke and Preece 2000).

The nature of online support groups can be highly variable, and dependent on a limited or select number of users or 'superusers', those responsible for generating much of the online content with the online group (O'Neil et al 2014). Conversations may also be monopolised by more dominant members or edited/deleted by group moderators (Chen 2013, Stommel and Kool 2010). The content of messages may also be dependent on the literacy levels of the person posting the message, which can affect how conversations develop. Posts that are badly written, hard to read and understand may not encourage responses from other members. Conversely, posts that are verbose and grandiose may have the same effect. Analysis of message postings provides limited information that people are willing to disclose at a particular time, and it has been suggested that this type of analysis is used in triangulation with other research methods such as surveys and interviews (Robinson 2001). This was the case for the current research where this method will be used to complement the findings from an online survey and semi-structured interview.

4.4 Ethical considerations in online research

Kassavou and Montgomery (2014) state that ethical considerations are unavoidable when conducting research in and practising health psychology. The British Psychological Society (BPS) in their Code of Human Research Ethics (BPS 2014) espouse four main ethical principles applicable to all research contexts that involve human participants -

- Respect for the autonomy and dignity of persons
- Scientific value
- Social responsibility
- Maximising benefit and minimising harm

There has been debate in the research community about the appositeness of these principles with regard to research involving the Internet, and the use of online communities as a source to collect data. To that end, the Ethics

Guidelines for Internet-mediated Research published by the British Psychological Society (2017) provide a supplemental contemporaneous guide relevant for researchers conducting online research. A summary of the main ethics issues researchers are encouraged to consider is presented in Table 1.

Table 1 - Summary of the main ethics issues to consider when designing, implementing or assessing an Internet-mediated study

Principles	Considerations
Respect for the autonomy and dignity of persons	***Public/private distinction*** – The extent to which potential data derived from online sources should be considered in the public or private domain; ***Confidentiality*** – Levels of risk to the confidentiality of participants' data, and how to minimise and/or inform participants of these risks, particularly where they may potentially lead to harm; ***Copyright*** – Copyright issues and data ownership, and when permission should be sought to use potential data sources; Valid consent – How to implement robust, traceable valid consent procedures; ***Withdrawal*** – How to implement robust procedures which allow participants to act on their rights to withdraw data; ***Debriefing*** – How to implement robust procedures which maximise the likelihood of participants receiving appropriate debrief information.
Scientific value	***Levels of control*** – How reduced levels of control may impact on the scientific value of a study, and how best to maximise levels of control where appropriate
Social responsibility	***Disruption of social structures*** – The extent to which proposed research study procedures and dissemination practices might disrupt/harm social groups
Maximising benefits and minimising harm	***Maximising benefits*** – How each of the issues mentioned above might act to reduce the benefits of a piece of research, and the best procedures for maximising benefits; ***Minimising harm*** – How each of the issues mentioned above might lead to potential harm, and the best procedures for minimising harm.

BPS (2017) Main Ethical Issues Concerning Internet-Mediated Research

The guidelines address ethical issues pertinent to research using the Internet, including the public-private domain distinction online; confidentiality and security of online data; procedures for obtaining valid consent; procedures for ensuring withdrawal rights and debriefing; levels of researcher control; and implications for scientific value and potential harm. How these are interpreted and executed is dependent on the type of study and research design.

The boundaries between public and private on the Internet are not clearly defined (Markham 2012, Sveningsson Elm 2009), but it has been argued that online support groups should be viewed as private spaces if interactions are characterised by high levels of emotion (Pfeil and Zaphiris 2010). In the case of diabetes online support groups, members have been shown to share highly personal and private information as they feel a sense of trust, commonality and cohesiveness. This sense of trust can be fostered by the perceived level of privacy members feel they have in the group, in particular if the group is identified as a 'closed' group, accessible to members only. Here people have to request to join an online group and they may be vetted or have to fulfil certain criteria before they are allowed to join. In closed groups, members may use log in details and a password as another level of security, which distinguishes the private group from the public domain. Other groups where there is no security in place and anyone is able to view posts and comments could therefore be deemed as public spaces.

Some online groups will clearly state the terms and conditions of membership if applicable, or set out rules for people to adhere by if they access the group. For example, certain online diabetes support groups will only allow people with diabetes to join and will ask for information appertaining to this at registration, including the type of diabetes, treatment used or even ask for details of the hospital/clinic they attend. If the criteria are not met, the group moderators may refuse entry. Nevertheless, this relies on people being honest and concerns have been raised by researchers about the authenticity of participants recruited online (Boydell et al 2014). This is of particular concern when carrying out research where the age of participants needs to be verified, i.e. research with children and young people (Rodham and Gavin 2006) or to meet the participant criteria as set out in the study design.

Individuals online may choose to conceal their true identity or change certain aspects including their age or gender (Levine et al 2011). Although it should be noted this is not an issue solely confined to online research, with researchers using pen and pencil questionnaires also reliant on participants giving honest answers.

The issue of confidentiality and security of online data is intrinsically linked with the debate surrounding the distinction between public and private domain on the Internet, but it not always possible to clearly delineate between the two even within individual online support groups (Roberts 2015). For example, the Diabetes UK online support group requires potential members to register with an email address that needs to be verified before they can post on any of the topic boards within the group. Nevertheless, the same group allows people who have not registered to view the boards. This means that information posted and possibly perceived by the poster as private due the fact they had to use measures to log in, could be 'cut and pasted' and shared with others. Even those groups who operate a more stringent membership policy or set out regulations prohibiting the sharing of posts on other boards cannot fully guarantee the confidentiality of members' data. This is an ethical grey area, that owes more to the logistics of how online communities are set up and operate and how other members behave, rather than a lack of compliance by researchers.

The type of study also has an effect on the notion of confidentially. When recruiting participants from a diabetes online support group to take part in a web-based survey, confidentiality can be better achieved by participants either being randomly assigned a unique user number or selecting their own user-name (Im and Chee 2012). For studies that involve thematic analysis of posts, if researchers publish quotes verbatim there is a risk that a Google search or other search engine could find the post and ultimately identify the poster (Boydell et al 2014). A way to reduce this is to use closed private groups that have a level of security in place that will not enable a search engine to find the post (Roberts 2015). It is also imperative that protocols regarding confidentiality ensure that data relating to a study is stored securely. The use of e-mails to correspond with others about the research or to share data could potentially breach confidentiality. Passing through unencrypted servers before they are delivered increases the risk of being viewed by someone other than the intended recipient (Kreindler 2008). A further risk is that e-mails may be sent to the wrong email account or read by the wrong person (Granberry 2007). Similarly, how data are stored may lead to confidentiality issues. Cloud storage is increasingly being used to store data, with information saved on remote servers. It can be accessed from different and multiple devices and shared between research colleagues. Remote storage of this type is open to malicious attack from hackers and personal or sensitive information can be stolen (Moura and Hutchison 2016).

Potential participants should be given information about the research they are invited to take part in, including details of how the data they provide will be stored and any probable risks by sharing information online before they decide to consent to participate. This informed consent process should be comparable to non-Internet mediated research, whilst acknowledging and making transparent to potential participants any limitations. Implementing robust informed consent procedures for participants is necessary when working with private online communities, where data are not considered to be in the public domain. This can be challenging as it may not be possible to contact certain group members if they are no longer active with the online group (Roberts 2015). With research involving analysis of messages posted on online support groups, group members may react badly when contacted for permission to use their message posts for the purpose of research (Hudson and Bruckman 2004). Smedley and Coulson (2018) caution this may produce feelings of resentment or distrust, and could have detrimental consequences for the participant if they decide to leave the online support group, meaning they no longer access the help required.

In line with The British Psychological Society Ethics Guidelines for Internet-mediated Research (2017), researchers have a responsibility to protect participants and should be alert to distress among participants online (Evan, Elford and Wiggins 2008). This may be challenging when there are no visual or audible cues, as in the case of a researcher posting details of a web-based survey on an online support group. Researchers using online focus groups should be attuned to alternative cues such as participants 'dropping out' of the online discussion or long periods of silence. It has been suggested this could be avoided by the researcher building a rapport with participants and providing them with a way of leaving the discussion that does not imply a level of distress (Eynon, Fry and Schroeder 2008). Evan, Elford and Wiggins (2008) suggest online research might make it easier for participants to discontinue their participation as they feel less obligated than if participating in face-to-face research. This may be viewed as a possible limitation of online research, but conversely, could assuage ethical concerns regarding participants right to withdraw from the research.

Another ethical consideration that relates to recruiting participants online is how the trustworthiness and authenticity of the researcher is established in the first instance. Direct contact by email or posting details on online support groups could be construed as spamming behaviour by some online communities (Mendelson 2007), leading to research requests being ignored. A suggestion to overcome this is by ensuring that institutional branding, such as hospital or university logos, is apparent on all types of requests for research participants. This helps satisfy participants of the authenticity of the request and to not dismiss recruitment attempts as spam.

'Netiquette' is also something to consider when approaching online support groups for research purposes. It describes a way of behaving in an appropriate manner online (Mann and Stewart 2000). Whilst general 'netiquette' rules have been identified and are customarily adhered to (see Shea 1994 for a comprehensive set of rules), there may be subtle variations within specific online communities. To that end, it is prudent to approach group administrators or moderators in the first instance before posting details of any research or research requests, and this applies to open or public online communities. In a study looking at the ethical consequences of employing virtual ethnography to observe behaviour in open online communities Wijaya, Watson and Bruce (2013) found that treating an open online group of Indonesian migrant workers hosted in Facebook as a private group helped the researchers engage within it. This strategy allowed them to not only obtain permission from the group leader to join the group, but to observe the group, identify potential participants, and by seeking informed consent, carry out interviews, capture posted messages, images and videos.

Identifying appropriate ways to approach and engage sympathetically with online support groups can enhance the intimacy of the researcher with the online group (Driscoll and Gregg 2010). Building this kind of rapport with online groups can be time consuming and does not guarantee that permission to access the group from administrators or moderators in their role as gatekeeper will be forthcoming. Conversely, obtaining permission from the moderators to post details of research on online support groups does not ensure that a positive response is forthcoming from other members of the group. If this disrupts the equilibrium of the group or has a negative effect, it is the ethical responsibility of the researcher to assess and best manage the situation in the most appropriate manner, guided by the tenets of the Ethics Guidelines for Internet-mediated Research (British Psychological Society 2017).

4.5 Summary

Choosing to utilise pragmatist assumptions and a mixed methods research design may present philosophical and technical challenges not as apparent in studies where only qualitative or quantitative methods are chosen. However, that should not preclude health psychologists and researchers from using mixed methods designs as this can help researchers develop an approach that best fits the research question. This chapter provided a rationale for choosing to adopt a mixed methods approach and has identified some of the considerations and issues that are pertinent to online research. Based on this, an online survey, semi-structured interviews and an analysis of messages posted to diabetes online support groups was employed to address the aims of the research. The succeeding Chapters 5, 6 and 7 provide a detailed description of each of the three empirical studies in this thesis.

Chapter 5: Study 1 - Exploring how parents of adolescents use diabetes online support groups: Results from an online survey

5.1 - Introduction

This chapter presents details of the methods and subsequent results of Study 1, an online survey completed by 88 parents from diabetes online support groups. The methodological strengths and weaknesses of using an online survey were previously discussed in Chapter 4, and the following chapter provides a detailed account of the procedures specific to Study 1, including recruitment, data collection and data analysis. The criteria for identifying appropriate online support groups for recruitment is identified and the structure of the online survey is discussed; the measures used appraised, and the internal consistency and validity of these considered and debated. This is followed by the results section where the response rate and the socio-demographic characteristics of the parents group is presented before the analysis of the measures employed are interpreted and then considered in the wider context of the literature surrounding online support groups for those effected by type 1 diabetes.

5.1.1 - Aims and objectives

The overall aim of the thesis was to explore how and why parents of an adolescent with type 1 diabetes choose to use diabetes online support groups during a time that has been shown to be particularly stressful for parent and child - the transition from paediatric to adult diabetes services during mid to late teens (NHS 2016). Furthermore, the research aims to explore if group membership empowers parents and affords any psychosocial benefits.

Study 1 aims to build on the limited literature surrounding online support group use by this cohort by using an online survey as part of a mixed methods research design. Whilst the survey is predominantly quantitative in nature, it includes open-ended questions to allow participants the opportunity to articulate their thoughts and perspectives. The objectives of the current study were -

- to gain a greater understanding of the motivations of parents for using diabetes online support groups.
- to identify the illness representations held by parents currently using diabetes online support groups.
- to investigate if using diabetes online support groups empower parents and the consequences of this.
- to identify if parents using diabetes online support groups show evidence of diabetes distress.

5.2 - Methods

Data for the current study were collected from a self-administered online survey of parents accessing diabetes online support groups. This was considered to be an effective and cost-efficient method of reaching the target population i.e. parents of adolescents with type 1 diabetes.

5.2.1 - Sampling and participant recruitment

Participants were recruited from a number of diabetes online support groups identified following an Internet search using the search engines Google, MSN, Bing, Yahoo, and the social networking site Facebook. The searches were carried out using combinations of the terms 'diabetes', 'type 1 diabetes', 'type 1', 'IDDM', and 'support group', 'forum', 'board', 'message board', 'online support group', 'online support', 'community', and 'parents', 'family', 'carer' and any other relevant synonyms and denotations of these. The following inclusion criteria were used for the study: i) the online group was asynchronous; ii) in English; iii) had a minimum of 50 members; iv) at least 25 messages had been posted within the previous month (Mo and Coulson 2012).

Both public and closed/private groups were included in the search as informed consent would be obtained from participants in accordance with University of Nottingham's code of research conduct and research ethics regulations and the British Psychological Society's ethics guidelines for Internet-mediated research (BPS 2017). The 'terms and conditions' of each group were inspected to verify if posting details of research studies or approaching members with research requests was permissible, 1 group explicitly stated this was forbidden and was therefore excluded.

Of the forty-two groups identified, twenty-five were eligible to be contacted, ranging in size from 180 to 152000 registered members. An administrator for each group was contacted by email to introduce this researcher and give details of the study before requesting permission to recruit participants from the group. For some groups, namely those that were closed groups, it was necessary to apply to join the group in the first instance to make contact with the administrators. In all cases where this was necessary, full disclosure was given as to the purpose of the application to join. Of the twenty-five administrators contacted, four from closed groups refused a request to join the group in order to share details of the research, citing privacy concerns for their members. Five group administrators refused to host the online survey as they felt it was at odds with the philosophy of the group, and sixteen granted permission.

Only when permission had been obtained from the group’s administrator was an introductory message posted on the board giving details of the study for members to view including the aims and objectives of the study as well as contact details of this researcher if anyone had any queries (Appendix A). Members were encouraged to share details of the survey with other group members or with people in other diabetes online support groups they frequented if this was permissible, and this type of virtual snowball sampling, has been shown to be successful in recruiting hard to reach or hidden populations on Facebook (Balter and Brunet 2012).

5.2.2 - Data Collection Tool

A hyperlink was highlighted at the end of the recruitment message that redirected prospective participants to the survey hosted by Bristol Online Survey (BOS). Bristol Online Survey (BOS) is a licensed online software package designed primarily for academic research, education and public sector organisations. It is a relatively easy to use service that facilitates the development, deployment and analysis of surveys via the Internet. Produced and run by Bristol University, it is compliant with all UK data protection laws and is the software package for generating online surveys authorised by the University of Nottingham for use by postgraduate research students and staff.

5.3 - The online survey

When participants clicked on the hyperlink, they were taken to the first page of the survey. They were presented with an information sheet giving details of the research project, the aims and objectives and the inclusion criteria. This was followed by confirmation of ethical approval, details regarding confidentiality of data and the right to withdraw from the study. Contact details of the researcher and both University of Nottingham supervisors were also included. The next page of the survey asked participants to read and respond to a series of questions to obtain informed consent electronically. Once consent had been confirmed, they were asked to create a unique password and keep the details for future reference. This was to identify their responses if they wished to have their data withdrawn from the study. Only when this had been submitted were they able to commence the survey. An example of the online survey is presented in Appendix B.

Details of the various sections of the survey including the individual scales and measures used are now presented in the order they appeared in the survey.

5.3.1 - Sociodemographic information

Participants were asked to provide sociodemographic information relating to age, gender, ethnicity, level of education, current employment status and relationship status. Questions relating to their child with type 1 diabetes, including sociodemographic information and health characteristics were included. This related to age at diagnosis, time since diagnosis and details of their diabetes management and current healthcare provider. Participants were also asked if they had been diagnosed or treated for depression, anxiety or any other mental health disorder within the last twelve months.

5.3.2 - IPQ-R Diabetes

The Revised Illness Perception Questionnaire (IPQ-R) is a revised version of the Illness Perception Questionnaire developed by Weinman et al 1996. It is a self-report survey instrument designed by Moss-Morris and colleagues (2002) to measure the components of illness representations described by Leventhal's Self-Regulatory model (SRM) (Leventhal et al 1985, 1997). It has been used to investigate an individual's cognitive and emotional representations and responses to illness or a threat to their health. Five core components have been shown to factor into illness perceptions, as reflected as subscales in the original Illness Perception Questionnaire (Weinman et al 1996): (1) *identity*: the label given to the illness or condition and the symptoms associated with it; (2) *timeline*: the predictive belief about how long the illness will last); (3) *consequences*: the long/short term personal, social or financial repercussions of the illness; (4) *cause*: factors that are the perceived cause of the illness; and (5) *curability/controllability*: the extent to which the illness could be cured or controlled and the degree to which the individual is instrumental in accomplishing this. The revised version of the Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al 2002) addressed minor psychometric problems with two existing subscales and introduced the additional subscales; illness coherence, cyclical timeline and emotional representations. In this form it has been validated and shown to have good internal reliability (Heijmans and Rijken 2003).

The IPQ-R (Moss-Morris et al 2002) comprises of three sections. The first is an identity subscale with 14 commonly experienced symptoms. This is followed by a section with 7 subscales: (1) timeline - acute/chronic (belief that the illness will last a long time, e.g., *my child's diabetes is likely to be permanent not temporary*); (2) consequences (beliefs about the consequences of diabetes, e.g., *my child's diabetes has major consequences on their life*); (3) personal control (belief that as a parent they could control/manage their child's diabetes, e.g., *what I do can determine if my child's diabetes gets better or worse)*; (4) treatment control (beliefs in efficacy of treatment to control/manage disease, e.g., *my child's treatment can control their diabetes*); (5) illness coherence, (the ability to understand diabetes so that it makes sense and is not confusing, e.g., *I have a clear understanding of my child's diabetes*); (6) timeline - cyclical (beliefs about the variability and unpredictability of diabetes, e.g., *my child's symptoms come and go in cycles*); and (7) emotional representations (degree of emotional impact of diabetes, e.g., *I get depressed when I think about my child's diabetes*). The final section contains a causal subscale with 18 items. It has also been adapted for a number of specific illnesses including, asthma, cystic fibrosis, diabetes, HIV, and rheumatoid arthritis. The IPQ-R Diabetes (IPQ-R D) was used for the online survey for Study 1 and the text was modified where necessary to make questions applicable to parents. For example, *'your diabetes*' was changed to *'your child's diabetes'.*

5.3.2.1 - Scoring the IPQ-R D

For the identity subscale, participants were presented with a list of 14 physical symptoms and asked if: i) their child had experienced any of the symptoms since their diagnosis of diabetes and ii) if they believed these symptoms were related to type 1 diabetes. A 'yes' or 'no' response was required. The 'yes' responses on symptoms related to diabetes were given a score of 1, with the 14 items summed to give an overall score. For the second section containing the 7 subscales, participants were asked to indicate how much they agreed or disagreed with statements about their child's illness using a 5-point Likert style scale (1-5): strongly, disagree, neither agree nor disagree, agree and strongly agree. This was repeated for the causal subscale, which consisted of

18 attributional items, similarly scored on a 5-point Likert style scale. Additionally, participants were asked to list the 3 most important factors they believed caused their child's diabetes. All items for each subscale, with the exception of the causal subscale that was analysed separately, were summed to give an overall score. High scores on the identity, timeline - acute/chronic and cyclical, consequences, and emotional representations dimensions signify strongly held beliefs, that symptoms observed are attributable to diabetes, that diabetes is chronic, that there are negative consequences associated with diabetes, that diabetes is cyclical in nature, and that there are negative feelings associated with diabetes. High scores on the personal control, treatment control, and illness coherence dimensions represent positive beliefs about the controllability of diabetes and the personal understanding of diabetes.

5.3.3 - Parent Diabetes Distress Scale (PDDS)

Diabetes distress has been defined as *'significant negative emotional reactions to the diagnosis of diabetes, threat of complications, self-management demands, unresponsive providers, and/or unsupportive interpersonal relationships'* (Gonzalez, Fisher and Polonsky 2011, pg. 236). These emotional reactions include anger, fear, frustration and guilt (Esbitt, Tanenbaum and Gonzalez 2013), and have been reported by parents managing or co-managing their child's diabetes as a response to the demands they face on a daily basis. These demands have been described as overwhelming; particularly reported at diagnosis, but also identified during times of change such as a moving from one healthcare team to another.

The literature on parental emotional distress in relation to diabetes has addressed the subject using a variety of definitions, such as depression, stress or anxiety (Whittemore et al 2012). However, little emphasis has been shown on the burdens and stresses that parents experiences as a specific consequence of their child’s diabetes, more aptly named as diabetes distress (DD) (Gonzalez, Fisher and Polonsky 2011). Fisher, Gonzalez and Polonsky

(2014) propose that unlike depression, diabetes distress is not a psychiatric condition. They contend that the diagnosis of depression is symptom based only, and the context of diabetes is not taken into account when considering the emotional distress that may be experienced by people affected by diabetes. Therefore, diabetes distress can be considered as part of the spectrum of diabetes rather than a distinct clinical psychiatric condition; it is an emotional response to the demands diabetes imposes (Berry, Lockhart, Davies et al 2015), that requires a separate measure that is diabetes specific.

To address this, Hessler, Fisher, Polonsky and Johnson (2016) developed The Parent Diabetes Distress Scale (PDDS). It is a relatively short 20 item self-report scale that highlights four critical dimensions of parental diabetes distress: (1) personal distress (relates to parents concerns about their personal quality of life, e.g. *'feeling that diabetes is taking up too much of my mental and physical energy everyday*'); (2) teen management distress (relates to parents concerns about their child's diabetes management, e.g. *'worrying about my child’s low blood sugars when he/she is away from home'*; (3) parent/teen relationship distress (relates to parental concerns about conflict with their child, e.g. *'feeling that trying to help my child with their diabetes is always a battle');* and (4) healthcare team distress (relates to the adequacy of their child’s health care, e.g. *'worrying that my child doesn't have the right healthcare team'*). The scale required no modification for the online survey.

5.3.3.1 - Scoring the PDDS

Participants were asked to answer 20 questions about how they had been feeling as a parent of teenager with diabetes using a 5-point Likert style scale with responses that ranged from 'not at all' to 'a great deal'. All items were summed to give a total overall score, with each of the 4 subscales summed individually. Mean scores between 0 - 1.9 suggest 'little or no distress', 2.0 - 2.9 suggest 'moderate distress' and scores $\geq$ 3.0 are indicative of 'high distress' (Hessler et al 2016).

5.3.4 - Use of the Internet and online support groups

Participants were asked to respond to questions about their Internet use in general. They were asked to select how often they used the Internet from a list of five possible options ranging from 'on a daily basis' to 'less than once a month'. Next, they were asked what they used the Internet for. Here participants were presented with a list of possible activities and asked to select those applicable to them. There was also an alternative 'other' option available where participants could specify activities not listed.

Participants were then asked to select if they had started using a diabetes online support group before or after their child's diabetes diagnosis, and to choose from a number of options to identify how they had discovered the group. Next, a series of questions were asked about participants diabetes online support group use. These included asking how long participants had belonged to their chosen diabetes online group, how frequently they visited the group and the amount of time spent per visit. They were asked to indicate if and how often they had posted messages on an online diabetes support group.

Participants were asked to respond to three open-ended questions about their experiences of using a diabetes online support group -

1. *Please say why you use diabetes online forums.*
2. *What do you think has been the most useful thing about using diabetes online forums?*
3. *What do you think has been the least helpful thing about using diabetes online forums?*

Using an open-ended format gave participants the opportunity to express their opinions in their own words and had the potential to identify issues most significant to the participant. The responses to the three questions were qualitatively analysed using inductive thematic analysis following the guidelines set out by Braun and Clarke (2006). In order to become familiar with the data, the responses from the participants were read multiple times. Notes were made during each reading to help generate initial ideas, leading to the generation of initial codes and eventual themes.

5.3.5 - Satisfaction with online support group use

Satisfaction of the diabetes online support groups' participants used was gauged by the responses to 4 questions scored on a 5-point Likert scale. The scale was derived from previous research that addressed levels of satisfaction in health-related online support groups (van Uden-Kraan et al 2009, Mo and Coulson 2010). Satisfaction with the support and information received, the ease of accessibility and the overall level of satisfaction were scored between 1 - 'very dissatisfied', 2 - 'satisfied', 3 - 'neither satisfied nor dissatisfied', 4 - 'satisfied' to 5 - 'very satisfied'.

5.3.6 - Empowering processes and outcomes

5.3.6.1 - Empowering processes

Empowering processes from online support group participation were measured by a 34-item scale. Items for this scale were adapted from the empowering processes scale developed by van Uden-Kraan et al (2008). The original scale contained 29 items measuring 5 dimensions of empowering processes: (1) exchanging information; (2) encountering emotional support; (3) finding recognition; (4) helping others; and (5) sharing experiences. 5 additional items were added to the scale to investigate parental notions of diabetes online support groups as a 'safe place', as Merkel and Wright (2012) suggested diabetes online groups could foster empowerment through the provision of a safe environment to share experiences of caring for a child with type 1 diabetes.

5.3.6.2 - Empowering Outcomes

Empowering outcomes were measured by a 37-item scale adapted from the scale by van Uden-Kraan et al (2009) and Mo and Coulson (2010). The van

Uden-Kraan and colleagues scale (2009) scale contained 38 items formulated to describe empowering outcomes from participating in online support groups. 7 dimensions were categorised: (1) being better informed; (2) feeling more confident in the relationship with their physician; (3) improved acceptance of the illness; (4) feeling more confident about the treatment; (5) increased optimism and control; (6) enhanced self-esteem; and (7) enhances social well-being. Mo and Coulson (2010) proposed a further dimension 'finding positive meaning' to the empowerment scale. 34 of the original items from the van Uden-Kraan et al scale and 3 items from the dimension added by Mo and Coulson were used.

5.3.6.3 - Scoring the empowering processes and outcomes scale

Where necessary, the phrasing of questions in both scales was modified to make them applicable to parents using diabetes online support groups rather than patients as in the original van Uden-Kraan et al study. For example, *'I feel better informed as a patient'* was changed to *'I feel better informed as a parent of a child with diabetes'*.

For the empowering processes scale participants were asked to rate the frequency of events they experienced within the online support group, for example, *'how often does it happen that someone in the diabetes online group you use most frequently reassures you?'*. The 34 items were rated using a 4-point Likert scale, with 1 - 'seldom to never', 2 - 'sometimes', 3 - 'regularly' and 4 - 'often'. The 5 additional items investigating if online support groups were perceived as a 'safe place' were prefaced with the question *'thinking about the diabetes online forum you use most frequently how much do you agree with the following statements?*', for example, *'my chosen diabetes online forum is a safe place to discuss my child's diabetes'* and rated using a 5-point Likert scale from 1 - 'completely disagree', 2 - 'disagree', 3 - neither agree nor disagree, 4 - 'agree' to 5 - 'completely agree'. A 5-point scale was chosen for these 5 questions as they were not measuring the frequency of events and it gave the respondent the opportunity to provide a neutral response if required (Johns 2005).

For the empowering outcomes scale of 37 items, participants were asked to rate the extent to which they agreed with statements about the possible outcomes of using online support groups, for example, *'to what extent would you agree that participating in a diabetes online support group has given you a better understanding of your child's diabetes?'* Each statement was rated using a 5-point Likert scale from 1 - 'completely disagree', 2 - 'disagree', 3 - neither agree nor disagree, 4 - ‘agree’ to 5 - 'completely agree'.

At the end of the survey, participants were asked if they would be interested in taking part in a follow up one to one interview, and if so they were asked to provide a contact email address. On the final page of the survey, participants were thanked for their help and the contact details of the researcher and supervisors were provided again.

5.4 - Ethical considerations

Ethical approval was obtained from the Faculty of Medical and Health Sciences' Research Ethics Committee at the University of Nottingham (reference A13112014). This was in accordance with the University research guidelines and the British Psychological Society's ethics guidelines for Internet-mediated research (BPS 2017).

In line with the BPS guidelines and in order to preserve the anonymity of each participant, any potentially identifying information was removed from the survey data. Additionally, the names and website addresses of the diabetes online support groups used in the study were not disclosed to further ensure participant confidentiality.

5.5 - Data analysis

Data analysis was carried out using SPSS v22 software package. All data was stored securely on an encrypted external hard drive and stored in a fire rated security safe.

5.6 - Results

The results from the online survey are presented in the first instance as a series of discrete sections detailing the analysis of the data collected from the socio-demographic questions, the IPQ-R Diabetes, the PDDS, the empowering processes and outcome scale and the 3 qualitative open-ended questions.

5.6.1 - Sample characteristics

100 participants completed the online survey. 12 participants reported their children as being below the age of 16. Further investigation of these completed questionnaires confirmed they did not meet the inclusion criteria, and they were removed from further analysis.

The demographic characteristics of the participants are shown in Table 2. The average age of the participants was 45.45 years (SD = 5.78), and the majority were female (n=87, 99%) with only 1 male participant. The majority were married or in a relationship (n=67, 76%) and lived with other people (n= 69, 78%). 58% (n=51) had tertiary education (n=51, 58%) and were employed either on a part time or full-time basis (n=66, 75%). Over a third of the participants reported they had been diagnosed or treated for a mental health problem, including depression and anxiety (n=32, 36%).

Table 2 - Socio-demographic characteristics of study 1 parents (N=88)

Variable	N=88 (%)
Gender	
Female	87 (98.9%)
Male	1 (1.1%)
Ethnicity	
White	87 (98.9%)
Black African	1 (1.1%)
Age	
Mean (SD)	45.45 (5.79)
Highest academic qualification	
GCSE / Standard	15 (17%)
A Level / Higher	22 (25%)
HNC	4 (4.5%)
HND	4 (4.5%)
Degree	35 (39.8%)
Postgraduate degree	7 (8%)
Other	1 (1.1%)
Relationship status	
Single	21 (23.8%)
Married / civil partnership	60 (68.2%)
In a relationship but living separately	7 (8%)
Living arrangements	
Live with spouse/partner	60 (68.2%)
Live with others	9 (10.2%)
Live alone	19 (21.6%)
Employment status	
Student	1 (1.1%)
Full time employment	25 (28.4%)
Part time employment	41 (46.6%)
Unemployed	10 (11.4%)
Homemaker	2 (2.3%)
Carer	5 (5.7%)
Retired	1 (1.1%)
Parents mental health	
Treated for depression	16 (18.2%)
Treated for anxiety	11 (12.5%)
Treated for other mental health disorder	5 (5.7%)

Participants provided details about their child with type 1 diabetes, shown below in Table 3. The average age was 16.22 years (SD = 1.47), with the average time since diagnosis being 6.48 years (SD = 3.95). There was a relatively equal division between genders, 46 female and 42 male (52% and 48% respectively). 48 (54.5%) attended a paediatric diabetes clinic, 20 (22.7%) attended a transition clinic and 13 (14.8%) attended a young adult clinic. The insulin delivery method was also identified, with similar results shown between pump and pen delivery (n= 46, 52.1% and n=41, 46.4% respectively), and only 1 participant reporting their child using syringes. Participants also reported if their child with type 1 diabetes had been diagnosed or treated for a mental health problem, including depression (n = 15, 17%), anxiety (n = 13, 14.4%), and an eating disorder (n = 2, 2.3%). Details about the numbers of other family members with type 1 (n = 21) and type 2 diabetes (n = 47) were also provided.

Table 3 - Characteristics of child with type 1 diabetes and other family members reported by parents (N=88)

Variables	**N = 88 (%)**
Age of child with type 1 diabetes	
Mean (SD)	16.22 (1.47)
Age at diagnosis	
Mean (SD)	9.75 (4.05)
Time since diagnosis	
Mean (SD)	6.48 (3.95)
Gender of child with type 1 diabetes	
Female	46 (52.3%)
Male	42 (47.7%)
Type of diabetes clinic attended	
Children's clinic	48 (54.5%)
Young adult clinic	13 (14.8%)
Transition clinic	20 (22.7%)
Does not attend clinic	2 (2.3%)
Other	5 (5.7%)
Insulin delivery method	
Syringe	1 (1.1%)
Pen	41 (46.6%)
Pump	46 (52.3%)

Variables	**N = 88 (%)**
Child with type 1 diabetes mental health	
Treated for depression	15 (17%)
Treated for anxiety	13 (14.8%)
Treated for eating disorder	2 (2.3%)
Other children in the household	76 (86.4%)
Other child with type 1 diabetes	3 (3.4%)
Family members with type 1 diabetes	
Grandparent	4 (4.5%)
Parent	2 (2.3%)
Aunt / Uncle	5 (5.7%)
Cousin	6 (6.8%)
Sibling	4 (4.5%)
Family members with type 2 diabetes	
Grandparent	20 (22.7%)
Parent	15 (17%)
Aunt / Uncle	10 (11.4%)
Cousin	2 (2.3%)

5.6.2 - Internet use and online support group use

The details of participants Internet use and diabetes online support group use are presented in Table 4. Almost all participants reported using the Internet on a daily basis (n = 86, 97.9%) for a variety of reasons including accessing emails, social media, online gaming, communicating via Skype and online shopping. With regard to diabetes online support groups very few participants identified they had accessed this type of group before their child's diagnosis (n = 2, 2.3%), with the majority using them after diagnosis (n = 86, 97.7%). The diabetes online support groups used by participants were initially identified mainly by means of an Internet search (n = 62, 70.5%) or recommended by a friend (n = 18, 20.5%), with recommendation from a healthcare professional reported as much lower (n = 8, 9.1%). The length of group membership ranged from < 3 months to > 5 years, with 42% of participants reporting group membership of 1-3 years, and almost 23% 3-5 years. The majority of participants visited diabetes online support groups at least once a day (n = 73, 82.9%), with time spent per visit reported as between 5-10 minutes by over 40% of participants, 15-30 minutes by 28%, and 30 - 60 minutes by 17%.

Longer periods of time spent on the online support groups were reported less frequently, with 10% of participants spending 1-2 hours per visit and only 3% spending longer than 2 hours. Whilst the majority of participants visited the OSG at least once a day, this frequency was not reflected in the number of messages posted, with only 15% (n=13) posting one or possibly several messages a day, 21% (n=19) posting messages once or twice a week, and 27% (n=24) posting once or twice a month.

Table 4 - Internet use and diabetes online support group use by study 1 parents (N=88)

Variables	**Total (N=88)**
Internet use	
Email	85 (96.6%)
Web browsing	80 (90.0%)
Online shopping	79 (89.9%)
Online gaming	12 (13.6%)
Instant messenger	46 (52.3%)
Chat rooms	10 (11.4%)
Blogs	13 (14.8%)
Social networking	84 (95.5%)
Skype	18 (20.5%)
Other	3 (3.4%)
Internet use frequency	
Every day	86 (97.7%)
At least 3 times a week	1 (1.1%)
Once a week	1 (1.15)
Initial use of diabetes online support groups	
Before child's diagnosis	2 (2.3%)
After child's diagnosis	86 (97.7%)
Diabetes online support groups identified by	
Internet search	62 (70.5%)
Told by a friend	18 (20.5%)
Told by Dr or nurse	8 (9.1%)
Advertisement	8 (9.1%)
Length of diabetes online support group membership	
< 3 months	7 (8%)
< 6 months	5 (5.7%)
< 1 year	7 (8.%)
1 - 3 years	37 (42%)
3 - 5 years	20 (22.7%)
> 5 years	12 (13.6%)
Visits to diabetes online support groups	
Daily	56 (63.6%)
Several times a day	11 (12.5%)

Variables	Total (N=88)
Once a day	6 (6.8%)
Several times a week	9 (10.2%)
Monthly	6 (6.8%)
Time spent on diabetes online support groups (per visit)	
5-10 minutes	36 (40.9%)
15-30 minutes	25 (28.4%)
30-60 minutes	15 (17%)
1-2 hours	9 (10.2%)
> 2 hours	3 (3.4%)
Messages posted on diabetes online support groups	
Once a day	4 (4.5%)
Several posts a day	9 (10.2%)
Once or twice a week	19 (21.6%)
Once or twice a month	24 (27.3%)
Once or twice	27 (30.7%)
No	5 (5.7%)

5.6.3 - Parents' impressions of using diabetes online support groups - responses to the open-ended questions

From the inductive thematic analysis of the data set from parents' responses to the three open-ended questions, the following themes were generated and labelled as -

- Exchanging Information
- Emotional Support
- Alliance
- Negative aspects

5.6.3.1 - Exchanging information

Many of the participants indicated they viewed their chosen diabetes forum or group as a valuable resource for searching for or sharing information about type 1 diabetes. This ranged from finding out about clinical aspects of the disease and disease management, to more practical or logistical issues of living with a child with diabetes. This participant said she used diabetes online support groups for:

> *'Confirmation of day to day issues of diabetes and a better understanding of possible things to watch for.'*
> (Participant 8250131[1] Female)

Another responded:

> *'You bring your child home from the hospital with a deadly disease, syringes, needles and no medical background...it's a great way to get share practical tips (what kind of belt to carry the pump in) and new medical ideas and technology.'* (Participant 9466036 Female)

Information appertaining to diabetes legislation shared on the online support groups was also beneficial to members, and participants reported they found it valuable for:

> *'Picking up tips and realising (about) laws etc. that apply.'*
> (Participant 8249393 Female)

> *'Without the forum I wouldn't have known about DLA.'*
> (Participant 8439269 Female)

Parents could also use the information available to get confirmation that the emotions and feelings they were experiencing were similar to those experienced by others, as this participant indicates when describing why she used a diabetes online support group:

> *'To help me understand what we need to do and give me as much information as possible on T1 diabetes. I also use it check that what we are feeling is normal.' (Participant 8251849 Female)*

Diabetes online support groups were also viewed as a place to acquire information that was relevant to parents looking forward to the future and

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[1] 7-digit identification number generated by Bristol Online Survey (BOS) software.

based on other members' anecdotal experiences. This participant used diabetes online support groups to get:

> *'...information especially about the next stage of my child's development and how other families cope - e.g. transition to secondary school, affect of puberty...'* (Participant 8298696 Female)

Some participants felt that the information available was greater, or of more use at times than that received from certain health professionals:

> *'These parents knowledge surpasses that of call handlers and nurses on NHS 24...They even help get a hold of supplies if someone is in urgent need. On the Freestyle Libre group...people share ideas and suggestions about how to overcome difficulties such as how to avoid it from falling off...as well as sharing new site areas that haven't been clinically approved yet.'* (Participant 8294197 Female)

> *'...it's vital info and advice found on these forums (provides) things that our medical specialists don't tell us.'* (Participant 8439344 Female)

5.6.3.2 - Emotional support

Emotional support was considered a highly positive aspect of accessing diabetes online support groups and it was a common theme advocated by many of the participants. Caring for a child with diabetes could be socially isolating for parents, setting them apart from friends and others in their face to face networks who did not have experience of living with the disease. For some, the diabetes online groups were the only place they felt supported. Connecting with others who had not only an understanding of diabetes, but also the issues and emotions that parents faced could help with feelings of loneliness:

> *'I don't have any support here. I don't know any other type 1 kids or parents in my community. Forum X (name redacted) is my most useful*

> *resource and has made my life so much easier.'* (Participant 8250788 Female)

> *'I used them as I had nowhere to turn to for support. I felt I was alone and that no one understood what I was going through.'* (Participant 8751098 Female)

Additionally, by virtue of the unique characteristics of online support groups previously discussed in Chapter 3, emotional support could be available for members to access online as and when they needed it. This could often be at an unsociable hour due to unpredictable complications of diabetes or diabetes management. Connecting with others who were going through similar experiences and could therefore understand and empathise with their anger or frustration helped validate how they were feeling:

> *'Constant support 24/7, when you're up at stupid o'clock in the night waiting for a hypo to come back up. There's always someone else online who's dealing with type 1. You can share, rant, help each other...these people make you feel normal again.'* (Participant 8255640 Female)

Parents co-managing their child's diabetes care went through many experiences and emotions that only other parents of diabetic children could truly understand and empathise with. This sense of homogeneity and apparent solidarity between group members was emotionally supportive. It helped build confidence during difficult times when parents doubted their own ability to manage the disease or felt emotionally overwrought:

> *'These people really understand what it is like to be the parent of a teen with type 1. I never feel judged, I feel totally supported...these two groups have helped me through many sticky patches and I know that I can count on someone being there pretty much 24/7.'* (Participant 9398387 Female)

> *'It's a lifeline! Strangers who know what you are going through reach out to help you...you need people who will get you through the 2am blood sugar checks who tell you, "you can do this" when you want to give up.'* (Participant 9466036 Female)

Other participants felt that due to the support available through the online groups they were able to discuss negative feelings or emotional issues in a safe environment with other members who would understand and not be judgemental:

> *'I feel other parents understand how I may be feeling, the difficulties, emotional roller coaster we go through...it's a place I can talk openly and safely about my son's diabetes...he doesn't like me talking about diabetes.'* (Participant 8252670 Female)

> *'Being able to vent my frustrations or insecurity (re caring for my child) without fear of judgement from other parents that actually understand how it feels.'* (Participant 8293020 Female)

Whilst many of the participants identified using diabetes online support groups as a means of gaining emotional support, the frequency of participants proffering support was far reported less frequently. It was interesting to note that some of the participants who were offering support had an administrative role within the diabetes online support groups. For example, this participant described why she used a diabetes online support group:

> *'I use them for support, but mostly to help others. I'm admin on a number of groups and I'm parent rep for (name redacted) and vice chair for the national network, so I support other families daily.'* (Participant 8255640 Female)

5.6.3.3 - Alliance

Participants showed recognition and acknowledged similarity with other diabetes online support group members due to their shared experience of dealing with a child with type 1 diabetes. This sense of 'not being the only one' when reading messages posted by other members had a positive effect for some, and gave others optimism for the future. This participant thought the most helpful thing about using diabetes online support groups was:

> *'having a laugh with others in the same situation, lightens the mood and realise that some families are worse of than us...type 1's that are struggling with depression, I do not have these problems so sometimes online forums can make you feel better about your own situation.'* (Participant 8666709 Female)

Similarly:

> *'Reading about other parents experiences has shown me I'm not alone in my feelings of guilt and worry and sadness, and that I'll come through those feelings.' (*Participant 9028177 Female)

This sense of shared diabetes experience could be reassuring and help alleviate feelings of loneliness, helplessness and emotional instability for some participants. For these participants the most helpful thing about using diabetes online support groups was:

> *'Knowing I am not alone in the struggle to manage child's diabetes, and the issues are very common.'* (Participant 8254081 Female)

> *'They have saved my sanity at times...makes me feel part of a big family while I struggle and have no support from those within reach...makes me feel less guilty about my inadequacy when sugars are all over the place despite doing everything correct.'* (Participant 8252309 Female)

5.6.3.4 - Negative aspects

Whilst participating in diabetes online support groups was viewed as a mostly positive beneficial experience for the majority of participants, there were some negative aspects reported. Misinformation about diabetes and information postulated as fact about treatment and cures was considered confusing and unhelpful, and could give rise to cruel or derogatory comments being posted, for example:

> *'There are some people who go on type 1 groups and spout rubbish about curing diabetes by eating okra and juicing veg, cos they are confusing it with type 2, and make nasty comments about our kids were fed crap, and that's why they got diabetes.'* (Participant 8255640 Female)

> *'Some people can be fanatical about diet plans and post unbalanced comments.'* (Participant 8293020 Female)

Different or conflicting information from different healthcare teams was also seen as something that could cause tension within the online group and lead to members feeling confused. This participant reported:

> *'We can post what we say works for us, treating hypo's etc., then people comment that we shouldn't use jelly babies or whatever...what I post is what our DSN tells us to try...careful to say "this is what we would do in this situation", that's better.'* (Participant 9299080 Female)

Whilst this response highlights the inconsistencies some group members have experienced:

> *'I always find it baffling that nurse in one area say one thing and nurses in another say another. Can't they all get on the same page?'* (Participant 8250308 Female)

Reading distressing stories about potential complications of diabetes was particularly stressful and made some participants anxious, for example:

> *'Some of the scare stories you read especially the dead in bed ones. I panic every night my daughter will not wake up. I am up 2-3 time in the night to check on her.'* (Participant 8250044 Female)
>
> *'Seeing the outcomes when things go wrong. I have two children with type 1 and I nearly left the forum because of the horror of what could happen.'* (Participant 8685031 Female)

However, for this participant, leaving the group was the way to avoid further emotional distress:

> *'I have come off forums for a while as it upsets me to see posts about new stories where a PWD has died, especially 'dead in bed' syndrome.'* (Participant 8439269 Female)

Seeing photographs of children who had been hospitalised due to diabetic complications posted on the support groups was distressing and unwarranted and as one participant remarked:

> *'we don't need to see sick kids we have our own.'* (Participant 8670458 Female)

Another negative aspect of participating in diabetes online support groups was the potential for disagreements between members due to differing opinions or a clash of personalities. It was suggested in some instances:

> *'People are too opinionated or following a particular agenda.'* (Participant 8296202 Female)

This type of attitude could have an affect on the dynamics within the group, making other members uncomfortable and potentially less likely to participate:

> *'Some people try to overpower others with their opinions and on occasion made other people feel inferior.'* (Participant 8661128 Female)

5.6.4 - Satisfaction with online support groups

Participants reported high levels of satisfaction regarding their diabetes online support group overall (M=4.47, SD=0.59). With high levels of satisfaction reported regarding accessibility and ease of use (M=4.5, SD=0.59), the information they received (M=4.40, SD=0.64) and the support provided within the group (M=4.36, SD=.69).

5.6.5 - Revised Illness Perceptions Questionnaire - Diabetes

The internal consistency of the IPQ-R D was ascertained by the use of Cronbach's alpha (α). This was calculated for each of the seven dimensions of illness representations: timeline (acute/chronic), consequences, personal control, treatment control, illness coherence, timeline (cyclical) and emotional representations. The classification of reliability scores determined by George and Mallory (2010) was applied, where $< 0.5\ \alpha$ was unacceptable, $0.6 \leq \alpha < 0.7$ was questionable, warranting further investigation, $0.7 \leq \alpha < 0.8$ was acceptable, $0.8 \leq \alpha < 0.9$ was good and $0.9 \leq \alpha$ was deemed excellent. The item-to-scale correlations and inter-correlations of items within a scale were also examined for each dimension to investigate if any items correlated above r=.80, indicating redundancy in the scale items.

Item analysis of each subscale was undertaken to determine if internal consistency was satisfactory or could be improved by removing individual items (Cohen and Swerdlik 2010). Two items were removed from the Timeline (acute/chronic) subscale, *'my child's diabetes will last a short time'* and *'my child's diabetes will improve in time'.* One item was removed from the Consequences subscale, *'my child's diabetes is a serious condition'.* Two items, *'child's treatment will be effective in curing their diabetes'* and *'little can be done to improve my child's diabetes'* were removed from the Treatment

Control subscale. One item was removed from the Illness Coherence subscale, *'my child's diabetes is a mystery to me',* and 1 item was removed from the Timeline (cyclical) subscale ' *my child's symptoms come and go in cycles'.*

The internal consistency of the 7 illness representation subscales was considered acceptable with the exception of the treatment control subscale which had a Cronbach's α =.57. The internal reliability of this subscale has been reported as low (Moss-Morris et al 2002, Chilcot et al 2012, Joshi, Dhungana and Subba 2015). It has been suggested this may be due to the fact that broad questions about whether treatment can control illness do not take into account the range of treatments patients may be receiving (Taylor et al 2018). Cronbach's α for the 14-item Identity subscale was calculated, and the final Cronbach's α score for each subscale are presented in Table 5, with an interpretation of the dimension scores presented in Table 6.

High scores on the Timeline (acute/chronic) (M=18.99, SD=2.37), Illness Coherence (M=16.10, SD=3.50), Consequences (M=19.16, SD=2.67) and Emotional Representation (M=23.67, SD=5.43) dimensions indicate parents believe their child's diabetes to be a life-long, often unpredictable condition, with significant consequences. The data demonstrates participants have a personal understanding of the disease and a positive belief in the effectiveness of the prescribed treatment. Whilst a high score on the Personal Control subscale (M=22.31, SD=3.91) signifies parental belief in their ability to help control or manage their child's diabetes, a similarly high score on the Emotional Representations subscale (M=23.67, SD=5.43) identified higher levels of emotional negative feelings; responses associated with the emotional impact of diabetes.

Table 5 - Descriptive Statistics and Cronbach's Alpha values of the Revised Illness Perception Questionnaire - Diabetes Subscales (N=88)

Dimension (subscale)	Number of items (n)	Possible score range	Mean (SD)	Cronbach's α
Identity	14	0-14	5.15 (3.22)	.80
Timeline (acute/chronic)	4	4-20	18.99 (2.37)	.68
Consequences	5	5-25	19.16 (2.67)	.70
Personal control	6	6-30	22.31 (3.91)	.71
Treatment control	3	3-15	11.20 (2.25)	.57
Illness coherence	4	4-20	16.10 (3.50)	.90
Timeline (cyclical)	3	3-15	11.18 (2.58)	.71
Emotional representations	6	6-30	23.67 (5.43)	.89

Table 6 - Interpretation of the IPQ-R diabetes dimension scores

Dimension	Interpretation
Higher dimension scores indicate parents have a stronger belief that...	
Identity	these specific symptoms are concomitant with type 1 diabetes
Timeline acute/chronic	type 1 diabetes is permanent not temporary, and will last a long time
Consequences	type 1 diabetes has major consequences on their child's life.
Personal control	they have confidence in their ability to help control their child's condition
Treatment control	their child's prescribed diabetes treatment is effective
Illness coherence	they have a greater understanding of their child's condition
Timeline cyclical	symptoms of type 1 diabetes can be unpredictable and fluctuate
Emotional representations	negative emotional feelings are associated with their child's condition

5.6.5.1 - Identity

To determine the validity of the range of symptoms included in the identity subscale, the frequency with which the different symptoms were endorsed was assessed, with the proviso that all symptoms be endorsed at least once (Moss-Morris et al 2002). All symptoms were endorsed by at least 2% of the participants. Tiredness was the most frequently endorsed symptom, with over 72% of participants identifying it as a symptom specific to their child's diabetes. Physical weakness, nausea, dizziness, and difficulty sleeping were symptoms endorsed by over 50% of the participants. Wheeziness as a symptom related to diabetes was endorsed by only 2% of participants. The results for all the symptoms are presented in Table 7.

Table 7 - Illness identity dimension of the IPQ-R Diabetes (n=88)

Symptom	***My child has experienced this symptom since their diagnosis of diabetes (%*** **'yes' responses)**	***I believe this symptom is related to their diabetes*** **(% 'yes' responses)**
Tiredness	87.5	72.7
Physical weakness	60.3	58
Nausea	71.6	54.5
Difficulty sleeping	62.5	50
Dizziness	56.8	50
Headaches	75	48.9
Upset stomach	70.5	45.5
Weight loss	43.2	42
Pain	68.2	35.2
Stiff joints	29.5	20.5
Breathlessness	36.4	14.8
Sore eyes	26.1	14.8
Sore throat	59.1	5.7
Wheeziness	11.4	2.3

5.6.5.2 - Causes

The 14 causal domain attributional items were divided into the 4 sub-sections used by Moss-Morris et al 2002: psychological attributions, risk factors, immunity and accident or chance. Descriptive statistics and the percentage of participants in agreement (either 'agreed' or 'strongly agreed') were calculated for each item. The results are reported in Table 8, with an interpretation of the scores displayed in Table 9. Higher scores indicate stronger beliefs in that item as a cause of type 1 diabetes. The data indicates participants have a strong belief that 'germ or virus' (M=3.78, 69.3%) followed by 'altered immunity' (M=3.23, 48.8%) and 'chance or bad luck' (M=3.05, 51.1%) were the possible cause of their child's condition. The following items had a low mean score and zero 'agree/strongly agree' responses from participants: 'diet', 'smoking', 'alcohol', 'aging’, ‘personality', 'own behaviour' and 'negative mental attitude'.

Table 8 - Descriptive statistics and scores of the IPQ-R Diabetes Cause Subscale (N=88)

Cause of child’s type 1 diabetes	Range of scores	Mean (SD)	Responses to (%) 'agree/strongly agree'
Psychological attributions -			
Stress or worry	1-5	1.90 (1.17)	12.5 / 2.3 (14.8)
Family problems or worries	1-5	1.41 (.87)	4.5 / 1.1 (5.6)
Emotional state - feeling sad, lonely, anxious	1-5	1.41 (.84)	3.4 / 1.1 (4.5)
Overwork	1-5	1.34 (.76)	2.3 / 1.1 (3.4)
Mental attitude - negative attitude	1-5	1.15 (.42)	0 / 0 (0)
Personality	1-5	1.15 (.42)	0 / 0 (0)
Accident/chance -			
Chance or bad luck	1-5	3.05 (1.45)	37.5 / 13.6 (51.1)
Accident or injury	1-5	1.19 (.52)	1.1 / 0 (1.1)
Immunity -			
Germ or virus	1-5	3.78 (1.18)	38.6 / 30.7 (69.3)
Altered immunity	1-5	3.23 (1.34)	31.8 / 17) (48.8)
Pollution in the environment	1-5	1.99 (1.11)	12.5 / 0 (12.5)
Risk factors -			
Hereditary - runs in family	1-5	2.23 (1.31)	14.8 / 5.7 (20.5)
Poor medical care in the past	1-5	1.33 (.72)	2.3 / 1.1 (3.4)
Aging	1-5	1.18 (.44)	0 / 0 (0)
Alcohol	1-5	1.16 (.45)	0 / 0 (0)
Smoking	1-5	1.14 (.38)	0 / 0 (0)
Diet or eating habits	1-5	1.32 (.56)	0 / 0 (0)
Their own behaviour	1-5	1.13 (.37)	0 / 0 (0)

Table 9 - Interpretation of the IPQ-R Diabetes causes scores

Dimension	Interpretation
Higher dimension scores indicates parents have a stronger belief that..	
Psychological attributions	the cause of their child's type 1 diabetes was psychological
Risk factors	their child's type 1 diabetes was caused by certain risk factors
Immunity	their child's type 1 diabetes was caused by altered immunity
Accident/Chance	their child's type 1 diabetes was caused by accident or chance

5.6.5.3 - Relationships between the IPQ-R D subscales

Pearson's correlation coefficients were computed to investigate the inter-relationships between the IPQ-R D subscales. The results are reported in Table 10. The Identity subscale was positively correlated with the Consequences, Timeline (cyclical), and Emotional Representations subscales. The Identity subscale was negatively correlated with the Treatment Control subscale. The Consequences subscale showed a moderate positive correlation with the Timeline (cyclical) and Emotional Representations subscales and a moderate negative correlation with the Treatment Control subscale, which had a moderate positive correlation with the Personal Control subscale.

Table 10 - Correlation Matrix of the IPQ-R Diabetes Dimensions

Dimension	1	2	3	4	5	6	7	8
1. Identity	1							
2. Timeline Acute/Chronic	-.037	1						
3. Consequences	.355**	.295**	1					
4. Personal Control	.061	.080	.003	1				
5. Treatment Control	-.355**	-.041	-.358**	.370**	1			
6. Illness Coherence	-.218*	.000	-.286**	.212*	.303**	1		
7. Timeline Cyclical	.368**	.006	.329**	-.058	-.318**	-.248*	1	
8. Emotional Representations	.391**	.042	.525**	-.086	-.241*	-.404**	.288**	1

* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed)

5.7 - Parent Diabetes Distress Scale (PDDS)

The internal consistency of the Parents Diabetes Distress Scale (PDDS) was ascertained by the use of Cronbach's alpha (α). This was calculated for the scale in total and each of the four dimensions of diabetes distress using the classification of reliability scores determined by George and Mallory (2010), described above. The item-to-scale correlations and inter-correlations of items within a scale were also examined for each dimension to investigate if any items correlated above r=.80, indicating redundancy in the scale items. The Cronbach's alpha (α) was satisfactory for each subscale, therefore no amendments were necessary. The final Cronbach's α scores, mean scores and standard deviations are presented in Table 11 with an interpretation of the dimension scores presented in Table 12.

Table 11 - Descriptive statistics and Cronbach's Alpha values of the Parents Diabetes Distress (PDDS) subscales

Dimension (subscale)	Number of items (n)	Range of scores (total low-high)	Mean (SD)	Cronbach's α
Personal distress	6	1-5 (6-30)	2.73 (.99)	.80
Teen management distress	4	1-5 (4-20)	3.67 (.95)	.76
Parent/teen relationship distress	8	1-5 (8-40)	2.56 (1.10)	.93
Healthcare team distress	2	1-5 (2-10)	1.81 (1.10)	.91
Total Scale	20	1-5 (20-100)	2.76 (.86)	.92

Table 12 - Interpretation of the Parents Diabetes Distress Subscale Scores

Parents Diabetes Distress Scale (PDDS) Subscales	Score Indications
Personal distress	Subscale mean score 0 - 1.9 = *'little or no distress'*
Teen management distress	Subscale mean score 2 - 2.9 = *'moderate distress'*
Parent/teen relationship distress	Subscale mean score ≥ 3 = *'high distress'*
Healthcare team distress	

The data shows that the 'teen management distress' subscale was scored most highly by participants (M=3.67, SD=.95) indicating 'high distress'. This was followed by 'personal distress' (M=2.73, SD=.99) and 'parent/teen relationship distress' (M=2.56, SD=1.10) indicating 'moderate distress'. The lowest score was on the 'healthcare team distress' subscale (M=1.81, SD=1.10) indicating 'little or no distress'. The scale total score was M=2.76, SD .86 indicating parents experienced moderate levels of diabetes distress overall.

5.7.1 - Relationships between the Parents Diabetes Distress subscales

To investigate interrelationships between the PDDS subscales, Pearson's correlation coefficients were computed and reported in Table 13. Correlations were shown between all the subscales, which indicates related, but distinct areas of distress. A strong correlation (>0.70) was found between parent/teen relationship distress and personal distress. Moderate (>0.30 - <0.60) correlations were present between personal distress, teen management distress and healthcare team distress. Similarly, teen management distress showed moderate correlation with parent/teen relationship distress and with healthcare team distress. A moderate correlation was shown between parent/teen relationship and healthcare team distress.

Table 13 - Correlation Matrix of the Parent Diabetes Distress Scale subscales (PDDS)

Dimension		1	2	3	4
1	Personal Distress	1			
2	Teen Management Distress	**.565****	1		
3	Parent /Teen Relationship Distress	**.687****	**.571****	1	
4	Healthcare team distress	**.440****	**.350****	**.328****	1

**. Correlation is significant at the 0.01 level (2-tailed)

5.8 - Empowering processes and Empowering Outcomes

5.8.1 - Empowering processes

The internal consistency of the empowering processes scale was ascertained by the use of Cronbach's alpha (α). Again, this was calculated for each dimension of the empowering processes scale, using the classification of reliability scores determined by George and Mallory (2010). The item-to-scale correlations and inter-correlations of items within a scale were also examined for each dimension to investigate if any items correlated above r=.80, indicating redundancy in the scale items. 1 item *'information exchanged is usable',* met this criteria and was removed from the Exchanging Information subscale. No further amendments were made to the remaining subscales. The final Cronbach's α scores, mean scores and standard deviations for each subscale are presented in Table 14.

Table 14 - Descriptive statistics and Cronbach's Alpha values of the Empowering Processes Subscales

Dimension	Number of items (n)	Range of scores (total low-high)	Mean (SD)	Cronbach's α
Exchanging information	8	1-4 (8-32)	3.06 (.60)	.90
Encountering emotional support	12	1-4 (12-48)	2.52 (.70)	.93
Finding recognition	4	1-4 (4-16)	3.00 (.66)	.77
Helping others	2	1-4 (2-8)	2.59 (.86)	.91
Sharing experiences	2	1-4 (2-8)	2.79 (.89)	.89
Finding a safe place	5	1-5 (5-25)	3.32 (.82)	.76

The empowering processes that were experienced most frequently by members of the diabetes online support groups were 'finding a safe place' (M=3.32, SD=.82), 'exchanging information' (M=3.06, SD=.60) and 'finding recognition' (M=3.00, SD=.66). Frequency distributions on the separate items within the subscales (Appendix C) revealed that 88% of participants agreed or strongly agreed their diabetes online support group was 'a safe place to discuss their child's diabetes', and 80% agreed or strongly agreed they ‘preferred to talk about diabetes with other online group members rather than friends’. Concerning the information exchanged in the online groups, it was regularly to often found to be understandable by 90% of participants, and reported to be regularly to often of added value to the information received from the healthcare team by 85% of participants. 88% of participants indicated they regularly to often recognised they were not the only one dealing with a child with diabetes, and 65% regularly to often recognised themselves in the stories of other group members.

Other empowering processes that were experienced less frequently in the diabetes online support groups were 'sharing experiences' (M=2.79, SD=.89) and 'helping others' (M=2.59, SD=.86). For example, 65% of participants indicated they regularly to often shared their experiences of diabetes on the support group. Moreover, almost half of the participants (49%) indicated they regularly to often provided advice and support to other members. 'Encountering emotional support' (M=2.52, SD=.70) was the least frequently occurring empowering process, with 70% of participants regularly to often feeling reassured by other group members.

5.8.2 - Empowering outcomes

The internal consistency of the empowering outcomes scale was ascertained by the use of Cronbach’s alpha (α). This was calculated for each dimension of the empowering outcomes scale, using the classification of reliability scores determined by George and Mallory (2010). The item-to-scale correlations and inter-correlations of items within a scale were also examined for each dimension to investigate if any items correlated above r=.80, indicating redundancy in the scale items. 1 item *'participating in forums helps you feel better informed as a parent of a child with diabetes'*, was removed from the 'Being better Informed' subscale due to being a redundant item. Similarly, 4 items were removed from the 'More confidence in relationship with the healthcare team' subscale due to correlating highly with other items in the dimension - *'participating in forums helps you feel more confident questioning* *decisions by healthcare team', 'participating in forums helps you feel more knowledgeable about which questions to ask', 'participating in forums helps you judge when your child needs help from the healthcare team'* and *'participating in forums helps you be knowledgeable about which questions to ask'.* A further redundant item, *'participating in forums has given you a more positive attitude towards yourself' was* removed from the 'Enhanced self-esteem' subscale. The final Cronbach's α scores, mean scores and standard deviations for each subscale are presented in Table 15.

Table 15 - Descriptive statistics and Cronbach's Alpha values of the Empowering Outcomes Subscales.

Dimension	**Number of items (n)**	**Range of scores (total low-high)**	**Mean (SD)**	**Cronbach's α**
Being better informed	3	1-5 (3-15)	4.12 (.83)	.87
Feeling more confident in the relationship with child's healthcare team	4	1-5 (4-20)	3.32 (.99)	.89
Improved acceptance of the illness	5	1-5 (5-25)	3.32 (.79)	.85
Feeling more confident about the treatment	5	1-5 (5-25)	3.54 (.83)	.90
Increased optimism and control over the future	8	1-5 (8-40)	3.15 (.57)	.77
Enhanced self-esteem	4	1-5 (4-20)	3.24 (.78)	.87
Enhanced social well-being	2	1-5 (2-10)	3.81 (.90)	.64

The empowering outcomes experienced to the strongest degree were 'being better informed' (M=4.12, SD=.83), 'enhanced social well-being' (M=3.81, SD=.90) and 'feeling more confident about the treatment' (M=3.54, SD .83). Analysis of the separate items within the subscales (Appendix D) revealed 89% of participants felt better informed because of participating in a diabetes online support group, which they indicated helped give them a clearer picture about the treatment options in the future (76%). Many of the participants (82%) reported they felt less lonely and had made new friends (52%) as a result of participating in an online support group. The majority of participants indicated that participating in diabetes online support groups helped them identify where to go for information (81%) and helped them feel more confident dealing with diabetes on their own (69%).

The empowering outcomes 'feeling more confident in the relationship with child's healthcare team’ (M=3.32, SD=.99), 'improved acceptance of the illness' (M=3.32, SD=.79) and 'enhanced self-esteem' (M=3.24, SD=.78) were experienced to a similar degree by participants. Over half the participants indicated that participating in online diabetes support groups helped them understand the information they received from their child's healthcare team (60%),and helped them better explain their needs at the diabetes clinic (59%). In total, 57% of the participants reported they were able to be more open about their child's diabetes as a result of participating in an online support group. Similarly, over half the participants (51%) indicated that participating in online support groups helped them to be more accepting of their child's diabetes. Some participants reported a more positive outlook on diabetes (59%) and a greater sense of self-esteem (44%) by participating in online support groups.

To a slightly lesser degree, participants experienced 'increased optimism and control over the future' (M=3.15, SD=.57), with 66% indicating online support groups had helped them feel better prepared for the future, and more in control over what was happening to their child (57%).

5.8.3 - Relationships between empowering processes and outcomes

To investigate the relationship between the processes that occurred within the diabetes online support groups and the outcomes, Pearson correlation coefficients were calculated and reported in Table 16. The majority of the processes that took place in the diabetes online support groups were significantly positively correlated with outcomes of participation and ranged from weak (<0.30) to moderate (>0.30 <0.60). The strongest correlation was shown between the process 'finding recognition' and the outcome 'improved acceptance of the illness' (r=.504, N=88, p<0.01). There was no significant correlation between the process 'sharing experiences' and outcome 'feeling more confident with the relationship with child's healthcare team', or the process 'helping others and outcome 'increased optimism and control over the future'.

Table 16 Pearson's correlation coefficients for the relationships between the empowering process and outcomes.

	Being better informed	Feeling more confident in the relationship with child's healthcare team	Improved acceptance of the illness	Feeling more confident about the treatment	Increased optimism and control over the future	Enhanced self-esteem	Enhanced social well-being
Exchanging information	.467**	.319**	.227*	.275**	.255*	.277**	.212*
Encountering emotional support	.418**	.280**	.461**	.388**	.325**	.399**	.483**
Finding recognition	.482**	.426**	.504**	.356**	.368**	.466**	.234**
Helping others	.291**	.216*	.224*	.269*	.185	.346**	.420**
Sharing experiences	.251*	.105	.333**	.272*	.295**	.302**	.405**
Finding a safe place	.482**	.379**	.424**	.410**	.380**	.368**	.361**

**. Correlation is significant at the 0.01 level (2-tailed)
*. Correlation is significant at the 0.05 level (2-tailed)

5.9 - Discussion

As the first of three empirical studies conducted to address the overall aims of the thesis, the main objectives of the current study was to identify the illness representations held by parents of adolescents with type 1 diabetes using diabetes online support groups, to investigate if there was evidence of diabetes distress and to explore if parents found using these support groups with unique characteristics empowering. Analysis of the data from the online survey indicated that parents using diabetes online support groups displayed evidence of diabetes distress, with this finding supported by the identification of negative illness representations. Furthermore, the data demonstrates parents feel empowered by using diabetes online support groups.

5.9.1 - Participant characteristics

The participants who completed the online survey were overwhelmingly mothers (n=87), with only 1 father identified. There are a number of contributing factors that may offer a possible explanation for the gender disparity found in the results. Mothers have been shown in the literature to be the predominant caregivers of children with type 1 diabetes, taking primary responsibility for their child's diabetes management (Sullivan-Bolyai et al 2003, Wennick and Hallstrom 2007, Dashiff et al 2009). The "constant vigilance" of caring for a child with diabetes (Sullivan-Bolyai et al 2003) has been linked to mothers experiencing higher levels of stress than fathers (Streisand et al 2008, Haugsvedt et al 2011, Helgeson et al 2012), and at risk for diminished psychological health (Maas-van Schaaijk et al 2013, Jaser, Linsky and Grey 2014). Furthermore, mothers are more likely to actively identify deficiencies in, and seek out, informational and social support relating to diabetes using the Internet and online support groups (Paterson and Brewer 2009, Balkhi et al 2014, Perrone et al 2015). In contrast, He and Dworkin (2015) suggest Internet use and online engagement by fathers tends to be for more general purposes. However, a small body of research investigating online support group use by fathers of children with spina bifida and brain tumours has drawn parallels with the benefits experienced by mothers using online support groups (Nicholas et al 2004, Nicholas et al 2012). With fathers shown to be involved in their child's diabetes care and reporting diabetes related stress (Dashiff, Morrison and Rowe 2008, Hilliard et al 2011, Limbers and Teasdale 2018) future research might investigate paternal diabetes online support group use, exploring fathers' experiences and any potential benefits thereof. Unfortunately, with fathers accounting for such a small number of survey responses (n=1), their perspectives on diabetes online support groups remain under-represented in this study.

5.9.2 - Illness perceptions

Analysis of the data from the diabetes specific revised illness perceptions questionnaire (Moss-Morris et al 2002) identified that parents using diabetes online support groups exhibited a strong understanding of diabetes and showed a degree of confidence in their child's clinical treatment alongside their own ability to help co-manage their child's condition. It could be reasoned that positive representations regarding diabetes are formed in part due to the exchange of information, social support and sense of belonging experienced with the online support groups, which has been evidenced in other Internet based chronic illness research (Barrera et al 2002, Ayers and Kronenfeld 2007, Chung 2014).

Nevertheless, the participants also reported negative perceptions about their child's diabetes, in particular, regarding the consequences of the condition. They also demonstrated strong emotional feelings that were related to diabetes, and illness perceptions such as these held by parents of a child with a chronic disease have been associated with reduced psychological health (Cousino and Hazen 2013, Gatzoyia et al 2014). For parents using diabetes online support groups there is a likelihood of reading about other parents' negative experiences alongside positive diabetes experiences, which could contribute to or increase levels of stress, fear and diabetes distress. However, from the responses to the three open-ended questions included in the survey it appears that whilst parents acknowledge the existence of negative or frightening information this did not discourage or dissuade many from using the online support group. These findings are similar to those found in a pilot study by Balkhi and colleagues in 2014, who suggested that forum membership was significantly related to the amount of parenting stress and hypoglycaemic fear parents experienced, but despite this participants still perceived knowledge gains and social support from participating in online support groups or forums.

5.9.3 - Diabetes Distress in Parents

Parents in the current study displayed evidence of diabetes distress, with their child's diabetes management the area that showed the highest level of diabetes distress, and the current health care team the area of least distress. During late adolescence and in preparation for the transition from paediatric to adult diabetes services within the NHS, diabetes management moves from the parent's direct control to the adolescent, and more autonomy is given to the individual who is encouraged to self-manage their diabetes. This can be frustrating for parents, who may feel anxious or fearful about how their child will handle their diabetes management (Schreiner, Brow and Philips 2000). Associations between parental diabetes distress and poor glycaemic control in adolescents have been identified (Law et al 2013, Rumburg 2015, Hessler et al 2016). Whilst this study is not able to corroborate these findings, the qualitative data from the online survey indicates parents have concerns about their child's diabetes management and fears about hypoglycaemic episodes and use diabetes online support groups to obtain information, support and reassurance as a way to assess and potentially cope with the diabetes distress.

5.9.4 - Empowerment

Using diabetes online support groups appears to be empowering for parents of adolescents with type 1 diabetes, be that by actively searching for, observing or interacting with other group members for emotional support, or by using the group as a repository of information that enables them to make changes in how they managed their child's diabetes (Balkhi et al 2014). The online groups were considered a 'safe place' or environment for parents to discuss various aspects of their child's diabetes with other people in similar circumstances, facing similar issues. For example, periodic episodes of loneliness have been reported by parents of children with diabetes (Paterson and Brewer 2009), but they experience a sense of belonging in an online community where there is solidarity and a common understanding founded through observed or shared experiences (Wright and Bell 2003).

The sense of being in a safe, communal, non-judgmental environment can give parents the confidence to disclose sensitive or private information about their child, or share their own feelings about how they are coping with the pressures of dealing with a child with a chronic condition. This has been shown to be empowering for parents of children with special needs who used support groups on Facebook (Ammari and Schoenebeck 2015), where they have reported feeling less judged online then they do among their family and other people offline. Similarly, this safe online environment gives parents the opportunity to divulge emotions and feelings without damaging social relationships or risk hurting others (Rodham, McCabe and Blake 2009, Attard and Coulson 2012). Additionally, this can have a positive effect on parents' psychological well-being and self-esteem. Whilst the stress and fears parents experience dealing with an adolescent with type 1 diabetes have been well documented in the literature (Driscoll et al 2016, Jaser, Linsky and Grey 2014, Berg et al 2013), using diabetes online support groups may make it easier for parents to accept the disease. This may lead to increased optimism about the future and relinquishing diabetes management control when they read other parents experiences. These findings corroborate previous research across a variety of conditions indicating participation in online support groups can empower members (van Uden-Kraan et al 2008, 2009, Coulson and Greenwood 2012, Campbell, Coulson and Buchanan 2013, Johnston et al 2013, Mo and Coulson 2014, Brady, Segar and Sanders 2017).

5.9.5 - Parents personal perspectives on using diabetes online support groups - qualitative responses to the open-ended questions

Responses to the three open ended questions in the survey identified that parents in this study appeared to be discerning when using diabetes online support groups by equating the information they found with and against their own personal situation, previous experiences and pre-existing diabetes knowledge. Information from the online support groups was not however taken at face value; the relevancy, accuracy and trustworthiness were factors considered by parents when looking for information or advice shared by other group members. Similar findings have been reported in a small number of studies addressing Internet use by parents with a chronically ill child (Oprescu et al 2013, Glenn 2015, Nicholl et al 2017). A pilot study by Balkhi and colleagues (2014) identified diabetes online support groups for parents not only as a strong source for disseminating information, but also as a venue where misinformation could be spread, albeit unintended due to the level of information. Whilst a possibility, there was no evidence of this in the survey data, with parents reporting a high score on the illness coherence subscale of the IPQ-R D.

'Value homophily', where groups members are drawn towards others with similar beliefs and perspectives (Centola and van de Rijt 2015) was in evidence in the responses to the open-ended questions, with parents articulating they value the support from other group members. This appears to influence how parents asses other members as a credible source of information, with the advice or information from less supportive or disruptive group members deemed less so.

5.9.6 - Study limitations

The study used an online survey as this was considered a convenient and apposite method of collecting data. However, certain limitations of the study should be made apparent. Firstly, participants were self-selected from a limited number of diabetes online support groups. From the data, it can be seen that participants reported high levels of satisfaction regarding the support they received from the group they used most frequently and had been active users for a number of years. It may be that individuals who have a more positive experience of using online support groups and frequent users or long-term group members are more likely to agree to participate in research as they have a positive view to promote. Parents who feel they get little benefit from the online support group or have become disengaged from the group may have little incentive to take part in research. Therefore, it is important to note the characteristics of this cohort and acknowledge these affect the generalizability of the findings.

Secondly, of note was the cross-sectional nature of the study design. By definition, this only explored the participants' perceptions and experiences of using diabetes online support groups at the time they completed the online survey. Accordingly, the resultant data could be influenced by a number of factors such as current concerns or issues about their child's diabetes, their own health and general mood or recent interactions on the diabetes online support group. To address this, future research could employ longitudinal studies that would afford access to participants' experiences at different points in time.

A further consideration with the study was that participants carried out the survey online anonymously using the Internet. Whilst they were able to do this at their convenience, it does mean the researcher does not have control of the environment or any external factors that could make completion problematic. Analysis of the 'respondent progress' data available from the Bristol Online Software (BOS) that hosted the online survey reveals that 1122 respondents accessed the first page (page 1 of 8) the information page and then left the survey. There were 82 instances of respondents moving on to the second page then abandoning the survey, 41 respondents abandoned the survey at page 4 and 17 respondents abandoned the survey at page 5. 100 respondents completed the entire survey and submitted their responses.

Whilst online surveys have been shown to suffer from lower response rates in comparison to other methods of data collection (Cho, Johnson and Vangeest 2013, Yarger et al 2013), it is difficult to determine the reason a participant will drop out of the survey. This could be related to slow or poor Internet connection that is frustrating and leads to a participant abandoning the survey part way through. Participants were not able to ask the researcher for clarification or assistance when they carried out the online survey, nor was the researcher able to encourage them to complete the whole survey.

5.10 - Conclusion

The empirical findings from this novel online survey provide a greater understanding about how and why parents of adolescents with type 1 diabetes use diabetes online support groups, and further serves to extend the limited knowledge that currently exists about the online experiences of this cohort. Parents were primarily motivated to join a diabetes online support group following their child's diagnosis, looking for informational and emotional support from others with first-hand diabetes experience and knowledge. Notwithstanding current NHS guidelines, which advocates for adolescent patients to become more autonomous in managing their diabetes, parents of adolescents continued to access and contribute to diabetes online support groups years after the diabetes diagnosis as they had a vested interest in their child's health, diabetes management and long-term prognosis. Furthermore, the illness perceptions of parents of a child with type 1 diabetes, a chronic and potentially life-threatening condition, also support and help explicate the reported levels of diabetes distress.

Promisingly, parents using diabetes online support groups experienced empowering processes and outcomes, corroborating previous research in other populations. Parents found the online groups to be a safe environment where they could seek out information and advice relating to diabetes from similar non-judgemental others, and could share their experiences and offer support to other group members. This sense of homophily within the online support groups was identified as important, and parents felt less isolated and lonely. Any negative aspects about participating in online groups such as misinformation about diabetes or personality clashes between members was far outweighed by the positive experiences and benefits participants reported. This demonstrates the potential benefits diabetes online support groups may have in nurturing and supporting parents as they negotiate relinquishing control of their child’s diabetes management during the transition into adult diabetes services.

Chapter 6: Study 2 - An exploration of parents' experiences of diabetes online support groups using qualitative one-to-one interviews

6.1 - Introduction

Results from the online survey presented in Chapter 5 indicated that for parents of adolescents with type 1 diabetes, their participation in diabetes online support groups may have a number of empowering consequences. These include being better informed about diabetes, more confidence in the treatments available, and a sense of feeling less lonely and isolated due to finding other parents in a similar situation to their own. Despite these reported positive consequences, the analysis of high levels of parental distress was evident. Whilst parents were first motivated to join an online support group following their child's diabetes diagnosis looking for information and support, it was not within the scope of the online survey nor the resultant data to identify what influences their continued participation in the group years after that event. However, it could be speculated that parental diabetes distress may be a contributing factor. To explore this further and gain a more in-depth insight into the online experiences of this cohort, the present study uses a qualitative interview method. One to one telephone interviews were conducted with thirteen participants who had previously completed the online survey discussed in Chapter 5.

6.2 - Methodology

6.2.1 - Study rationale and aims

The rationale for the current study as part of the mixed methods approach adopted for this thesis was to build on the findings from the previous online survey. Exploring parents' personal experiences of using diabetes online support groups would provide a greater breadth and depth of understanding about the role online support groups have for parents co-managing this chronic disease. Specifically, the aim of this second empirical study was to investigate further and better understand what motivates parents to use a diabetes online support group, and the perceived benefits and consequences of this.

6.2.2 - Methods

In order to address the aims of the study a qualitative approach was adopted. Semi-structured one to one telephone interviews were conducted, with a data driven inductive thematic analysis carried out on the resultant data.

6.2.2.1 - Thematic analysis

The purpose of a thematic analysis is to interpret meanings of an experience, rather than quantifying frequencies (Braun and Clarke 2013). In contrast to other analytic qualitative methods such as grounded theory or interpretive phenomenological analysis (IPA), it does not require detailed theoretical and technological knowledge of approaches. This theoretical and epistemological independence makes it a more flexible form of analysis that can be used within different theoretical frameworks; arguably where its strength lies (Javadi and Zarea 2016). Conversely, this has led to some criticism being levied against it for being too flexible, leading to inconsistency and a lack of coherence when developing themes from the data (Holloway and Todres 2003). This can be addressed by the researcher identifying the epistemological position that coherently underpins the study's empirical claims (Holloway and Todres 2003).

For the present study, the thematic analysis was conducted within a realist/essentialist paradigm to reflect the meaning of the participants assumed reality evident in the data (Braun and Clarke 2006). A data-driven inductive thematic analysis was used to explore the experiences of parents using diabetes online support groups, and address the research question of what motivates parents to use these online groups. This was chosen in contrast to a deductive approach as it avoids the risk of rigidity and premature closure when coding the data using a pre-existing coding frame. The researcher is not constrained by predetermined theory and concepts (Boyatzis 1998, Braun and Clarke 2006), and this allows for the unexpected to be identified from the data.

6.2.3 - Participants

Participants for the present study were recruited from the 88 participants who had previously completed the online survey presented in Study 1 (see Chapter 5 for recruitment details). At the end of the online survey, participants were asked if they would be interested in taking part in a follow up one-to-one interview with this researcher. If so they were asked to supply an email address so they could be contacted with further details. 41 email addresses were collected from the online survey data and an email invitation with details of the interview study was sent. Those who replied confirming their interest in taking part were sent an information sheet and consent form via email (see Appendix E), and a mutually convenient time was arranged to conduct the telephone interview.

Seventeen participants initially agreed to take part in a one to one telephone interview. Three participants cancelled their scheduled interview beforehand and did not want to reschedule to a later date. One participant was not contactable on the agreed date and did not respond to any further email communications.

The demographics of the final group of participants (n=13) were all female, aged 35 to 52 (mean = 45 years). Eleven were married, 1 was in a recent relationship living separately from her partner, and 1 was single. Six participants worked part time, 5 worked full time; including 2 who were registered as full time carers for a family member, and 2 reported they were unemployed. Five participants had been members of a diabetes online support group for longer than 3 years, 5 between 1-3 years, and 3 had been for a year or less. The majority of participants reported using the online support group on a daily basis (n=10) and all reported posting messages.

6.2.4 - Data collection

Semi-structured telephone interviews were chosen as the data collection method for this study. The rationale for this decision was that participants of diabetes online support groups could be located in disparate geographical areas within the UK, and it was therefore more convenient to carry out telephone interviews.

A semi-structured interview schedule was developed to help guide each interview (see Appendix F). The interview began by asking the participant to briefly describe the circumstances of their child's diagnosis of type 1 diabetes and the types of information and support they had received at the time. Questions about their decision to use diabetes online support groups were then introduced. Further questions explored their preferences of how they used the group; if they posted messages or just read other members posts, how they chose to interact with other group members and if they had experienced any personal advantages or disadvantages using a diabetes online support group and the consequences of this. Their expectations about using diabetes online support groups in the future were also discussed. It should be noted that the interview schedule was used a guide, not a prescriptive itinerary, to help structure and give momentum to the interview. Participants were encouraged to ask questions at any time and put forward their own thoughts and opinions during the interview, which gave them the opportunity to provide detailed narratives (Holloway and Jefferson 2000) How they responded to questions often directed or redirected the flow and structure of the interview (Dyer 2006).

Thirteen semi-structured telephone interviews were carried out and digitally recorded via a computer using Skype 'Call Recorder' software. A second external Sony digital recorder was used to create an additional back up recording in the event of any computer failure. The data was saved in MP3 format and stored securely on an encrypted hard drive. Before each interview, participants were asked if they had read and understood the information sheet and consent form, and were then given the opportunity to ask any questions. They were reminded they were not obliged to answer any questions they did not wish to, and could take a break or stop the interview by alerting the researcher. The audio recording was then started and participants were asked to verbally give their consent for the recording. The interviews lasted between 31 and 55 minutes (mean 39 minutes). Whilst thirteen interviewees is a relatively small sample, data saturation was achieved. This was indicated at the point when there was repetition of issues across the interview data and no new information or potential themes were evident (Guest, Bunce and Johnson 2006).

The data was transcribed verbatim into Microsoft Word documents. It was cleaned of any identifiers and each participant was subsequently given a numerical label to differentiate between the participants. All transcription was carried out by this researcher to safeguard confidentially and all printed transcripts were stored in a locked filing cabinet.

During the interviews, notes were taken as a backup in the event of the digital recorder or external microphone failing (Easton, McComish and Greenberg 2000). At the end of each interview when the recorder was switched off, additional notes were made if necessary. This was another useful source of data, which enriched the recorded interviews, as participants would sometimes add a comment to something they had previously said after the recording stopped. Making descriptive notes after an interview afforded an efficient, yet meaningful combination of interview, observation and conceptualization. This further helped identify possible emerging themes or issues that had arisen during the interview, and these could be explored further with successive participants during their interview. Keeping records of the raw data, interview transcripts and additional field notes helped create a physical research audit trail, important for establishing research confirmability, trustworthiness (Koch 2006) and as a means of assuring quality in qualitative research (Akkerman et al 2006).

6.2.5 - Ethical considerations

Throughout the development, execution and analysis of the study a number of key ethical issues were considered related to issues surrounding confidentially and dealing with personal or sensitive issues. Participants who had responded to the invitation to take part in a telephone interview were emailed an information sheet that gave comprehensive details of the study, the participation process, and the process for withdrawing from the study at any time. Details of how audio data and transcribed interviews would be stored securely was also provided, along with an explanation of how the data would be used as part of a PhD thesis and possible academic journals or conferences in the future. Participants were assured that all data would be anonymised, and any identifying information would be removed to protect the participant’s identity. Additionally, any identifying details regarding specific diabetes online support groups used by participants would be removed. The contact details of this researcher and supervisory team at the University of Nottingham were included, should participants have any concerns or further questions. There were no queries raised by any of the participants.

Along with the information sheet, participants were emailed a consent form (Appendix E) and asked to indicate by ticking the relevant checkbox they understood the details on the information sheet, were happy to take part in an interview that would be recorded, and gave permission for anonymised quotes to be used in the final study report. The consent form was returned to this researcher by email and hard copies were stored in a locked filing cabinet. All email correspondence between this researcher and participants were kept in a separate file on a password protected email account on the University of Nottingham's centrally managed servers.

Whilst it was not anticipated that participants would find taking part in a telephone interview distressing, it was acknowledged that the participants were parents living with a child with a chronic health condition, therefore the interview process could include discussing potentially sensitive or upsetting issues. If a participant became upset or distressed during the interview, all steps were taken to reduce the negative impact, and participants were asked if they would like to take a break, postpone or stop the interview.

Ethical approval was obtained from the Faculty of Medical and Health Sciences' Research Ethics Committee at the University of Nottingham (reference N08122015). This was in accordance with the University research guidelines and the British Psychological Society's ethics guidelines for Internet-mediated research (BPS 2017). The BPS guidelines advocate that the normal principles of ethical research with human participants continue to be adhered to, whilst acknowledging that the implications of these principles may differ in the context of Internet mediated research due to the characteristics of online environments.

In line with the BPS guidelines and in order to preserve the anonymity of each participant, any potentially identifying information was removed from the transcribed interview data. Additionally, the names of diabetes online support groups used by participants were redacted when the data was transcribed to further ensure participant confidentiality.

6.2.6 - Data analysis

Thematic analysis of the transcribed telephone interviews was carried out in accordance with the guidelines set out by Braun and Clarke (2006). Figure 2 shows the six-phase process followed. Whilst presented here in a linear format, thematic analysis should be acknowledged as an iterative and reflective process that develops over time and necessitates the researcher moving back and forward between phases (Nowell et al 2017).

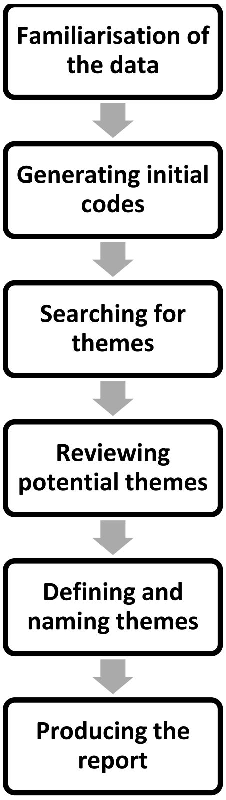

Figure 2 - Phases of thematic analysis (adapted from Braun and Clarke 2006)

As the data was not coded into an existing framework and in keeping with the adopted epistemological position noted previously, it was subject to inductive 'bottom up' analysis. This would ensure themes identified were data-driven and not as a consequence of pre-determined expectations (Boyatzis 1998). In the first instance, the interview audio data was listened to and the transcriptions were read and re-read whilst notes were taken. This was to allow this researcher to become familiar with the data. Next, initial codes were identified. These identify a feature of the data that is interesting to the researcher, and are ‘the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon’ (Boyatzis 1998 p.63). Codes were then collated and organised into potential themes. At this point, it was extremely beneficial to write the codes on different coloured Post-It notes and arrange these on an OA sheet of paper. This allowed for a visual representation of themes to be created (with references to relevant data attached), appraised by this researcher and then re-assessed or re-assigned to another theme if necessary. The themes were reviewed and refined before they were named in such a way as to immediately identify what the theme related to, the “essence” of what they comprised (Braun and Clarke 2006, p. 92). To enhance the validity of the findings, an independent researcher with extensive experience of qualitative analysis read each interview transcript and corroborated the final themes identified.

6.2.7 - The role of the researcher

Given the interpretive nature of qualitative methodologies, conducting qualitative research should be viewed as a reflexive process, and it would be disingenuous for the researcher not to acknowledge they are unable to exclude themselves from the cycle of data collection, interpretation and reporting (Holloway and Biley 2011). It is therefore pertinent to address the role I have as a researcher and acknowledge that the philosophical beliefs and implicit assumptions I hold may influence that research process. This can be achieved through reflexivity; with the caveat that by being reflexive, interpretations of others’ interpretations are governed by the way they (the researcher) construct and manage their realities. As Guba and Lincoln illustrate:

> “*An inevitable element in the inquiry mix is the values of the inquirer and a whole variety of other persons in and around the inquiry. Inquirers are human and cannot escape their humanness. That is, they cannot by an act of will set aside their subjectivity, nor can they stand outside the arena of humanness created by the other persons involved.”* (Guba and Lincoln, 1989, pg. 88)

In this way, researchers may strive to maintain integrity. Situating oneself socially and emotionally in relation to participants is an important element of reflexivity (Mauthner and Doucet 2003, Råheim et al 2016). This is particularly pertinent to the present qualitative study where there was bi-directional contact with participants who like myself were a mother. However, it would be mendacious to claim this shared role allowed me to socially situate myself with the mothers who participated in this study. It is necessary as a researcher to acknowledge my personal ontological beliefs and values and epistemological position, which falls within a pragmatic paradigm, and reflect on how these may influence my relationship (however transient) with the participants.

Before the start of each interview, I tried to put participants at ease by having a general 'ice-breaker' conversation. The majority of participants wanted to know why I had chosen type 1 diabetes as a condition to focus my research on, and if I had any first-hand experience of living with a child with diabetes. It was at my discretion how much personal information I divulged, but I was comfortable when asked, to disclose I had a family history of both type 1 and type 2 diabetes. All the participants asked if I was a parent and how old my child was. Again, I was happy to share basic information about my own daughter. Whilst I do not pretend to fully understand or be privy to the experiences that the participants in the current study shared with me, I am able to use my own role as a mother to relate their experiences into a framework of my experiences and constructed knowledge that enables me to appreciate the storied nature of their lives.

My previous research experience with children and young people had given me an awareness of how some researchers within this arena may adopt a variety of sub-roles within their 'researcher' role, such as 'least adult' or 'non authoritarian adult' (Randall 2012). However, caution must be taken if researchers adopt 'roles within a role' as it may be interpreted as the researcher being deceitful to elicit information. I was aware of this when disclosing my maternal status and family history of diabetes and was conscious of trying not to use it to ingratiate myself with participants. Such reflexivity whilst desirable is not always easy to achieve. This can lead to methodological angst where the researcher considers abandoning or rejecting the perspectives that shape their view in order to try to understand the others perspective (Guillemin and Gillam 2004).

My academic and health psychology background was of interest to a number of the participants, in particular, the fact my PhD was located in the School of Medicine at the University of Nottingham. It was important to clarify to participants that I came from a researcher not a practitioner background, as on more than one occasion I was asked for advice about new or different treatments for diabetes and recommendations for psychological therapies. When this happened, I would inform the participant that I was not qualified to give them this advice, but would ask them why they were interested in that issue and where they would go to look for the information. I believe this gave the participant the opportunity to explain what they felt they needed, and gave me as researcher a greater insight into their experiences of living with a child with diabetes.

6.3 - Results

The following themes were generated from the data and labelled '*It was like a bolt from the blue*', '*help I need somebody*', *'learning from the experts', 'I get by with a little help from my friends'* and *'It's a rational fear'*. These will now be discussed individually.

Illustrative quotations from participants have been edited to remove identifying information such as personal names, geographical locations and details. Where necessary, quotations have been abridged for brevity, indicated by the use of an ellipsis in the text.

6.3.1 - 'It was like a bolt from the blue'

6.3.1.1 - The impact of diagnosis

All the participants interviewed described the circumstances that led to their child’s diagnosis of type 1 diabetes as being the catalyst for them choosing to use a diabetes online support group. This provided a historical context during the interview, and a sense of temporality where they located their diabetes online support group experiences in the past (pre-diagnosis), present (post-diagnosis) and the future. All spoke of the sequence of events that eventually led to a clinical diagnosis of type 1 diabetes as traumatic, as it typically followed an urgent or sudden decline in their child's health. The speed of how quickly this happened was mentioned by most participants during the interview and was articulated by this participant whose son was symptomatic and diagnosed with diabetes within a week:

> *'It was sort of a quick diagnosis, really, just, probably seven days, he was getting up in the night to wee, and, um, he was tired, and he was drinking a lot. We travelled to _____ to go shopping, which is about half an hour away, and he went asleep on the journey, and then as soon as we got there, he needed the loo, and I felt something wasn't right... So on the fifth day I decided to get a doctor's appointment, and on that day he also woke up with a rash over his torso, and I knew that was pretty fundamental. So we saw a GP in the afternoon, and he was admitted straight away onto paediatric unit.'* (Participant 6)

Similarly, this participant's daughter was unwell and visited the GP twice in three days, where she was initially diagnosed with tonsillitis:

> *'She got sick on Monday...she did say she didn't feel very well, and her throat was sore, so I phoned the doctor, took her there, and they said she has tonsillitis, which she does get quite often. So, I brought her back home, they never gave me any medications...from then she just gradually went downhill, she wouldn't eat, she constantly went to the toilet, the only thing she would do is drink, and that lasted the Tuesday and the Wednesday. She slept for most of the time, just waking up to go to the toilet and have a drink. On the Wednesday, she started being sick, so I took her back then to the doctor, and the doctor said, "Oh yeah, definitely tonsillitis." She had no fever, nothing else was wrong with her, so I questioned them and I said, "Are you sure tonsillitis? She*

> *has no fever, and she's being sick." So, she said, "Oh yes, common with tonsillitis, and all that." ... on Wednesday evening, she started acting very strange, and felt delirious.'* (Participant 9)

As her daughter's health continued to deteriorate this participant went back to the GP surgery for a third consultation, where a different doctor did a finger prick to test blood glucose levels and she was admitted to hospital immediately:

> *'It was absolutely awful, and I'm not even gonna lie, but by the time we got to the hospital her organs were starting to shut down. The doctors, they took her up to, the intensive care ward... took her straight there and started pumping her with I don't even know what...we were in hospital for five days, and that was the worst five days I've ever spent. It was just absolutely awful, she had over 60 blood tests, and it was just a complete nightmare.'* (Participant 9)

What is apparent from this participant's recollection of her child's ill health before the diagnosis of type 1 diabetes is that the clinical presentation in children can be complex. Clinicians may diagnose and treat for other more common childhood illnesses in the first instance before testing for diabetes. This observation was evident in other participants' accounts, with some critical of the clinical judgement and advice given by healthcare professionals. In certain instances this had delayed a diagnosis of diabetes and necessary treatment. This delay further added to the level of anxiety and distress already experienced by parents when caring for an ill child. The following participant described how when her son's teachers brought changes in his behaviour to her attention, she had contacted her GP, but received only general advice and had to contend with coping with her son's symptoms for longer than necessary:

> *'I kept getting notes saying he wasn't concentrating, and he wouldn't participate...and he was generally a lazy boy...they said he's starving*

> *hungry and accused me of not giving him breakfast every day, which was delightful.'* (Participant 12)

> *'I rang the GP and said, "My son is really sort of tired and confused over simple things," "Oh, and is he weeing, and wetting the bed, and all that, very thirsty?" And I said, "No," and she said, "Oh well, come back if that's still on." Looking back, it was terrible advice. So two weeks later the inevitable, he was weeing all day at the shopping centre, and drinking. I had a doctor appointment on the Monday... Um, terrifying I'm looking back, I should've taken him on the Saturday, or to the hospital, or something, but anyway, I took him in on the Monday. He wet the bed all weekend, and, she did-- she was quite cross but did a urine test and then went into panic mode. (It was) a horrible experience with the GP sort of flapping around, cause she knew, really, she should have seen him two weeks before.'* (Participant 12)

This participant had a similar experience when visiting a GP after having concerns about her 2 year-old daughter's health, with the GP appearing to have a limited experience or understanding of paediatric diabetes, despite the prevalence and severity of the condition:

> *'She was two, so I don't know whether she was feeling iller than normal. She didn't say, we thought she just had a virus. But then she started drinking loads of water and weeing through her nappies, which is quite a difficult thing to do. So we took her to the doctor. He thought she had a virus too and wasn't really listening. He sent her up to the hospital for a blood test and I said you know, "do you think it could be diabetes?" ...but he didn't, he was a locum, it was after work, and he didn't think that you could get diabetes when you were two. So, he considered it extremely unlikely.'* (Participant 5)

Likewise, this participant's experience of dealing with health care professionals when her daughter was ill was problematic, involving numerous consultations:

> *‘She was ill from February, just randomly not well, not herself, losing weight, refusing to eat, drinking gallons of water... backwards and forwards to the doctor, “you’re just a fussy mum, she’s just going through normal childhood.” I said, "look, you have to do something, she's lost a hell of a lot of weight, and I’m really worried about her.” Refused to do anything about it, back again five days later, cause she was crying constantly if we even tried to pick her up or anything, to be told “She’s just fussy, you just need to stop worrying.”* (Participant 2)

She felt judged as a parent, which added to the stress she was experiencing, but defended her actions and felt were justified:

> *‘I did say to them “check the records and see how many times I’ve been with my three children in the last couple of years”, because I don’t take them unless it’s, you know, death’s door, erm, but they-- they just missed the signs completely.’* (Participant 2)

Whilst a number of participants said they had used the Internet prior to visiting a doctor to check the symptoms their child was exhibiting and had suspected type 1 diabetes, none reported accessing a diabetes specific online support group before they had received a positive diagnosis.

At the time of diagnosis, participants reported receiving varying levels of information and support, in the first instance received from the medical team in a number of guises including leaflets, books, details of clinics and diabetes specialist personnel. For some this was overwhelming when they were still coming to terms with trying to process and make sense of a life-changing event. This participant spoke about how she felt burdened by all the information she was given by the diabetes nurse looking after her daughter, and the pressure to understand everything in a short space of time when she had no previous experience of diabetes:

> *‘It was far too much, because from day one... she came with all of that equipment like blood monitors, finger prick, different types of insulin, and I was just there looking like, “What?” I have no idea... and she told me how the body’s going to be affected and I just looked at her like, “What?” ... “You’re going to have to inject her, you’re going to have to do this, you’re going to have to--”, and I was like, “What? I can’t do this.” I did not have a clue, and I just felt like overload, you know, too much.’ (Participant 9)*

As this extract shows, some participants appreciated getting information in a simple less complicated way they were able to process at a stressful time:

> *'We were given a book, a basic book that the team had put together, very simple form, pictures, and introduced to all the nurses very quickly, and phone numbers, and pens, insulin, everything.' (Participant 10)*

However, it was not always possible for the medical team to be on hand to explain things as this participant found when her son was admitted to the hospital over the weekend, and this had the potential to lead to confusion or conflicting information being given:

> *‘We didn’t see a diabetic nurse because she wasn’t on until the Monday… so we didn’t see anybody here with a specialist in diabetes, apart from the consultant who was an ordinary one... so we saw everybody on the Monday, which was a bit rubbish, that’s the only thing that I’d say was bad about it, it was because they gave us the information, they gave us leaflets and stuff, saying you have to have injections before you ate, and all, so you kind of self-taught from the leaflets over the weekend, but then the general nurses were, “Oh it’s lunchtime, here’s lunch,” and I said, “He hasn’t had his bloods done and he hasn’t had insulin” and they’re, “Oh he’ll be fine.” And so they would, you know, it was like the leaflet said one thing, the hospital was*

> *doing another.'* (Participant 11)

Some participants felt a sense of relief after diagnosis to finally know what was wrong with their child, and to be able to place it in context, as this participant recounted:

> *'It has a name, it has experience, it has a range of equipment, and medication, it has support groups, you know, it has charities based on it...'* (Participant 8)

However, this relief appeared to be short-lived as the logistical realities of managing diabetes and the emotional pressure on parents became apparent, as these participants described:

> *'You know the intensity of having a new born baby, when you really just don't know what you're doing, and you really are slightly driven out of your mind by the whole experience of it, and the sheer exhaustion etc. It's got some similarities, sleep deprivation, it's really insane, torture.'* (Participant 13)

> *'It was a nightmare, and it still is...she wouldn't let me check her blood, she wouldn't let me inject her, I had to chase her around the house, I couldn't inject her sometimes because I was too scared, too scared to give insulin, cause I thought it was going to kill her if I gave her too much, and it was awful. It still is about now, and I actually, I'm on-going with a psychiatrist now, because of her.'* (Participant 9)

6.3.2 - 'Help I need somebody'

6.3.2.1 - Isolation and the search for similar others

Participants described how after their child had been diagnosed with type 1 diabetes, they felt isolated and alone, even from other family members and friends, who lacked understanding and empathy:

> *'We found the family buried their heads at first, they didn't realise how*

> *serious it was, and when they did, they all backed away.'*
> (Participant 2)

They had turned to diabetes online support groups in an attempt to find other people in the same situation as them; people who shared similar experiences relating to type 1 diabetes and therefore had a better understanding of the consequences of having a child with this chronic health condition. As these quotes illustrate, group membership gave participants a sense of belonging; an alliance that was considered supportive by the commonality of experiences:

> *'Because they're usually parents who are going through roughly the same sort of things, and the same sort of times, um, whereas my family don't really understand it, and I don't have any family locally anyway...so it's talking to somebody who understands, what's happening, and understands it in depth from your perspective.'* (Participant 7)

> *'Sometime you just need to go, "ah, that's been a crap night, I'm shattered, and I've not slept" and it's not just when you say it to friends or family and they go, "Oh, yeah, I was up with the baby last night as well" and you think, "you haven't got a clue, you haven't got a clue. I was up for three hours with an injection in my hand, thinking I was going to have to call an ambulance." There's always that someone actually knows what you're going through.'* (Participant 2)

A sense of camaraderie was evident in the diabetes online support groups for new members, and this was considered beneficial by many at a stressful time. This mother spoke about the welcoming reception she received when she joined an online support group a few weeks after her daughter's diagnosis:

> *'the minute I went on this group and said, "You know, my daughter's just been diagnosed... it was just, "We've been there, this is what it's*

> *like, don't panic, you'll be OK"...it was like someone had a virtual arm around me, guiding me...I could never imagine any of the circumstance where I'd be that comfortable with a stranger, but they knew exactly what I was going through...I felt normal again, because there was other people out there dealing with what we were dealing with.'* (Participant 12)

Other group members empathised with her daughter's recent diagnosis, and whilst these people were 'virtual' strangers and unknown to her at this point in time, this homophily among group members had a positive effect on her emotional well-being.

Participants spoke about how they had experienced negative reactions from other people offline, including family members and friends, when disclosing their child had type 1 diabetes. This was often related to other people's misinformation about the cause of type 1 diabetes or a confusion between type 1 and type 2. This was distressing for parents to hear, and they reported they felt they were being judged, seen as *'bad parents'*, or even viewed as someway instrumental in their child's illness due to allowing them a poor diet by people who had little or no appreciation of the facts. As this participant angrily recounted:

> *'I get very annoyed with people when they assume that he is diabetic because of some failing of my part, or neglect on his part, because he is a healthy young man, he runs marathons, and does skydiving... I mean, two people said to me when, I told them that he'd been diagnosed with type 1 diabetes, one person said "oh, he had too many sweets" and another said "too many fizzy drinks, then."* (Participant 1)

Therefore, many of the participants had joined diabetes online support groups because they wanted to find other likeminded parents who could understand their child's illness without fear of judgement or reprisal, as these quotes demonstrate:

> *'Feeling that you can talk to people without being judged...sites are used by other parents who are non-judgmental, and they're only interested in trying to share information and advice.'* (Participant 13)

> *'Everyone here understands the condition, there's no blame, or having to justify.'* (Participant 1)

6.3.3 - 'Learning from the experts'

6.3.3.1 - Practical support

Diabetes online support groups were viewed by all the participants interviewed as a valuable source of information and practical support. This was considered particularly beneficial in the early days following diagnosis when parents were unsure about or struggling with the clinical complexities of managing a child with type 1 diabetes. Whilst healthcare professionals were cited in the main as offering excellent clinical support and expertise, they were not always available 24 hours a day, unlike the diabetes online support groups. The asynchronous nature of the online support groups provided accessible practical support that made many participants feel more reassured when they were dealing with physical problems or complications arising from diabetes during the night or early hours of the morning. As this participant described:

> *'But it's often practical advice that helps... so if you're up at three o'clock in the morning and you haven't had any sleep, and your child is hugely high or hugely low, being able to post either there and then...and then, talking about, or thinking of maybe changing this part of the treatment, or that part of the treatment, or doing something different, and have people go, "Oh, yeah, I did that already, do the other…"... it makes you feel a bit less-- not the weird one, the odd one out.' (Participant 8)*

Similarly, during the interview this participant spoke about having issues with her daughter who had been prone to hypoglycaemic episodes when first diagnosed. Her lack of experience meant she was unsure whether to adjust her daughter's insulin dose, and she had posted a message asking for help on the online support group in the early hours of the morning and received a numbers of replies and advice shortly afterwards about how to calculate the correct dosage. For her, the information that came from other group members was not only practical in terms of helping her deal with her daughter's medication, but it also helped her confidence:

> *'Knowing that at three o'clock in the morning, when I'm up with (___) there's somebody there, cause part of my issue was the lack of confidence, you know, I'd think, Oh, I'll give her too much, and I won't know what to do, and-- or that I won't give her enough, and she'd be really high, and-- I didn't have enough confidence to give her what she needed, and I always thought that giving her 20 units was a lot, but it's not.'* (Participant 10)

Participants spoke of the medical advice they encountered through the online support groups, either by reading other members posts about their experiences or in response to direct questions they or others had posted, as extremely beneficial as other members had a wide breath of diabetes related knowledge:

> *'Oh, there are members on there who know everything. I put a question recently, because my son's insulin prescription was changed, only had a couple of boxes of his old prescription sitting here in the fridge, and I said, you know, "What can I do with this? You know, do I have to take it back to the pharmacy? Can I donate it to someone?" And someone immediately came up with, "There's a charity that takes unused, unopened insulin, and distribute it in countries where they don't have a national health service." ...she came up with the address, within a day.'* (Participant 1)

The advice proffered on the online support groups did not supplant the advice from healthcare professionals. As it came from other members living with diabetes and with first-hand knowledge and experience of the issues and problems, many considered it to be trustworthy:

> *'This is people who all know the stuff...you learn about developments in diabetes management, and breakthroughs, medical breakthroughs type stuff, and that's the stuff that the parents will usually send you a message about.'* (Participant 13)

In addition, some participants commented that as they became more confident and experienced in dealing with their child's diabetes, and had been a group member for a while, they had shared medically related information and advice on the online support group. This included information about the different types of insulin available and details of new equipment such as pumps or monitors. Participants explained this was shared judiciously and with caution, and board members would often pre-empt their advice or experiences with:

> *'This is what happened for us, it might not happen for you, or your child might not react in the same way, but this has worked for us.' (Participant 7)*

There was a notion of careful sharing and vigilance around the content, which was self-monitored by other group members, and messages advocating potentially harmful treatments or selling cures were reported to the group moderators for action as this quote illustrates:

> *'So if I see something in someone's post a "drink cucumber juice and you're cured," I'll email the admin and say, "You need to remove that." I will step in... I will find the link to something that one of the consultants has done, or a piece of evidence, or something else, I won't tell the person they're wrong, but I'll let the person who asked the*

> *question know that it's wrong by posting the link and saying, "Please read this from, you know, the such and such university, or the so and so hospital, this is the evidence to prove that this is what happens, or this is what". So, sometimes you have to, sometimes we have to even block people from groups, because they are insistent that they know better, and that if you give them money, they can prove to you your doctor's wrong, and they can cure it.'* (Participant 2)

By the same token, whilst there was trust amongst group members, the credibility and reliability of the medical advice on the online support groups was not taken lightly or at face value. It was questioned and challenged where necessary:

> *'There's something that concerns me... about people giving specific medical treatment advice on social media. So you'll get people posting, "My child is 21, and I've been told not to correct them over night, but this has been going on," and people would say, "Give him a unit." So, hand on a minute, you don't know how old this child is, how heavy they are, what their normal dose of insulin is, and you're just giving an arbitrary, very specific piece of advice. If you give general advice about what you might do, and add in, you know, "You really ought to call your team about this as soon as possible," it's different. But then on other occasions you'll get people post that their child's vomited five times in the last six hours, that blood sugar is 28, and they will get a long line of, "Take him to the hospital now. If you can't get there yourself, call an ambulance, do it now." And it's frightening, the way that, um, people will turn to social media first in what can be a life threatening situation, but also that people can give what could be life threatening advice and not think about it.' (Participant 8)*

As well as the medical information shared on the online support groups, participants appreciated the more practical information other group members shared. Many spoke of the difficulties they had encountered when trying to find out if they were entitled to claim disability-related financial support, including benefits, tax credits, payments, grants and concessions for their child. This was reported as stressful and demoralising for some parents, but there were diabetes online support groups that provided a repository of suitable information, with members experienced in dealing with the necessary paperwork and red tape, as this participant's quote illustrates:

> *'There's another site as well that I'm a member of, but this has to do with disability living allowance…that's really, really useful, because children have the right to DLA, basically, because it's so different around the country, as to where the people get it, or not get it, and you have to fight for it, and that one is amazing, because they help you with things like submitting your forms, going for appeals, and things like that, and they say what happened to them, and how-- what they used.'* (participant 3)

Likewise, participants noted that their requirements for practical information about diabetes changed as their child grew older and their needs changed, and this was reflected in the diabetes online support groups some chose to use:

> *'Well, I think it's like all things in life, you move on to where your child is, so obviously I've gone through the DLA thing, and they're paramount to me now, it was through exams, but, you know, a three-year olds needs on social media, it's completely different, so you turn to migrate to the groups that you need.'* (Participant 10)

As parents of adolescents with diabetes, the participants in the current study reported an interest in finding out information about preparing their child for life at college or university. This was in order to make them more responsible for their own diabetes management. This raised different parental concerns, and again, group members sharing tips and hints was considered helpful for those parents with limited knowledge, with some participants reporting joining additional diabetes online support groups that catered for a specific age group or concern:

> *'There's another specialist group for parents whose kids are at university, which I'm in as well, and that's been really useful. Thinking about what that's going to be like, and what they're going to need, and how you have to plan for it.'* (Participant 5)

With regards to how they would use diabetes online support groups in the future as their children moved into adult diabetes services, became more autonomous and possibly left home, participants were cautious about permanently leaving the groups but accepted they might not access them as often as they had done:

> *'I think I probably won't need it as much when he's older now... I've seen that with other people with children who turn 18, 19, you hear a bit about them going off to college, and then they sort of fade away a bit, you know.'* (Participant 12)

Some reported they would still use the online groups but on a purely ad hoc basis, but others anticipated continuing to be active members to help parents who had recently joined the group, thus promoting advocacy among members.

6.3.4 - *'I get by with a little help from my friends'*

6.3.4.1 - Emotional Support

Many of the participants interviewed reported feeling overwhelmed and emotional following their child's life changing diagnosis of type 1 diabetes, as this quote demonstrates:

> *'We were emotionally unstable as it was when she was diagnosed, cause of how ill she was...we just only had the head space to deal with what we were dealing with right in front of us.'* (Participant 4)

The emotional response that stemmed from having a child with type 1 diabetes was extreme and not to be underestimated for some participants. The impact of receiving a diagnosis of diabetes extended beyond the consequences for the patient, with potentially serious ramifications for parents noted:

> *'If I didn't have that group, I don't know what I would've done. I actually felt like killing myself at one point...I did not have a clue what I was doing...But if I didn't have that group, I don't know where I would be, and I honestly don't.'* (Participant 9)

Accessing diabetes online support groups provided participants with emotional support whilst they came to terms with negotiating the practicalities of co-managing their child's health. The online groups were regarded as a safe welcoming environment where parents could share their emotions with other people who would understand what they were going through. This was particularly beneficial at the start of what one participant called *'our diabetes journey'* when she had joined a diabetes online support group a week after her son was diagnosed:

> *'In those early years, I don't think I'd have been sane still if I hadn't have the support from those people online...I was a mess, just crying all the time.'* (Participant 1)

Some participants felt the emotional support they received from their family and friends was insufficient, or they did not really understand what they were having to deal with. Managing friends and relatives emotional expectations was an added stress which did not occur on the online support groups due to other members being in a similar situation. As this participant explains when talking about the emotional support she encountered on a diabetes online support group:

> *‘I think when you need the emotional support it’s good to have it. And there isn’t anyone else really who understands in the same way. It’s no good, and I’ve long since given up talking to any of my friends about that sort of thing. I talk to my sister about it sometimes, but because of course she’s my daughter’s aunt, she just gets upset and worried too. If she’s too close to the problem in that respect. Erm, so they’re great, because they understand.’* (Participant 5)

Similarly, this participant found the emotional support from the online support group surpassed that of her family:

> *‘A few women friended me online, within hours, they’ve sent me their numbers, their emails, and they assured me I could ring them day or night, and a couple of them, I did contact in the middle of the night, and they were there for me, and they’re still my very best friends now. Other than my husband we found the family buried their heads at first, they didn’t realize how serious it was, and when they did, they all backed away, and sort of, “Oh, we don’t think we could do that,” and we’ve not really had much to do with them since.’ (Participant 1)*

The emotional support offered here appears to be unconditional and available as and when required, in contrast to that from other family members.

The speed which emotional support was offered to new group members was commented on during a number of interviews. Participants reported they had felt nervous when they joined an online support group, but were made to feel welcome immediately by other members who posted 'welcome to the group' messages, which showed empathy, compassion and helped reassure them. This participant described the response she received when she posted for the first time:

> *‘Welcome to the group, we’re really sorry, be kind to yourself, you know, take each day at a time, ask any question you want, no question’s too silly, we’ve all been where you are.’* (participant 10)

with similar responses articulated by other participants.

Participants who had been long standing members of the diabetes online support groups also spoke of the altruistic benefits of giving emotional support to other members of the group. They had received emotional support when they had first joined the group, and were grateful for this. Giving support to new members was a way to 'give something back' to the group and when discussing how she often offers practical help about dealing with the mechanics of type 1 diabetes to parents of newly diagnosed children, this participant disclosed:

> *‘Sometimes I actually personally go further, that would be, you know, virtual hugs, um towards the posters. Someone comes on and says “you know I’m feeling really down” then that’s fair enough to say “I’m sorry you’re feeling like that” or “sending hugs” or “wish you were closer” and all these kind of things.’* (Participant 5)

6.3.5 - *'It's a rational fear'*

6.3.5.1 - Emotional burdens

Participants spoke of the emotional burdens they personally faced when coping with their child’s diabetes. Feelings of loss, sadness and most noticeably fear were evident during the interviews. Receiving the initial diagnosis of diabetes and realising their child's health status would be forever changed had a significant impact and was likened to a bereavement, with feelings of grief and loss. As this participant explained:

> *‘It’s all your emotions, it’s-- maybe that you go through, it’s almost like a grieving process, isn’t it so? Yeah, it is, it’s a grieving for the health of*

> *your child, that has gone, it's a different way of life and that.'* (Participant 3)

There was sadness and resignation reflected when participants acknowledged the life changing quality that diabetes had on their life and the life of their child. Sometimes reading other parents experiences on the online support groups could bring this into sharp focus, as this participant described:

> *'Scared and sad, because I think, "Well that's me, that's my life," and sometimes it hits home, you know, you forget sometimes, and then you read something, you're like, "Oh my God."* (Participant 9)

Fear was the pervading emotion participants described when discussing the daily diabetes regimen they managed or co-managed with their child. The responsibility for making potentially life and death decisions when dealing with the physical burden of diabetes was acknowledged to be stressful and frightening. Fear of hypoglycaemia and the consequences of this was a common theme expressed by parents, and it was reported as an issue they often encountered on the diabetes online support groups, either by reading other members posts or posting messages themselves, asking for information or sharing their own experiences. As this interview extract demonstrates, this participant been advised by her daughter's healthcare team that it was not necessary to test her blood sugar levels throughout the night, however, on this occasion she was exhibiting signs of hypoglycaemia:

> *'In the middle of the night, she was like 2.3, and her eyes were rolling, and her head, and I was absolutely petrified, and I went online at three-thirty in the morning, and said, "What could I do?" and I had 50 replies within three hours in the middle of the night, cause these parents were all up night testing and that's when I realised, and I was like, "Well, why are you checking it?" and they said, "For the same reason you'll now check every night..."* (Participant 2)

Whilst the situation itself was terrifying, the response from the diabetes online support group appeared swift and informative. Because of this experience and the cautionary forewarning from other group members this participant decided to make significant changes with regard to her daughter's clinical care:

> *‘So, we moved to a team who supported and agreed that we should be checking during the night, and I think that’s a massive part of why I trust this online community so much, because none of them said, “You should do this, you have to do this,” it’s just very gentle, “This is what we do, this is how we found it when, erm, this is what happened to us, but everybody is different,”... you start thinking, well, actually, I need to take note of this, you know.’* (Participant 2)

However, some information and details of the negative experiences shared on the diabetes online support groups had the potential to add to the fear and trepidation for some members, particularly those new to the group or parents of newly diagnosed children. As this participants caveat regarding distressing content in the online support groups highlights, caution should be employed at times when using the online support groups:

> ‘*We were emotionally unstable as it was when she was diagnosed, cause of how ill she was, without knowing all the other crap... just be careful when you use them, you’re going to find stuff that’s going to scare you, and some of the scary stuff is valid, but you don’t need, you know, the scary stuff all on the first day... ‘* (Participant 4)

The ultimate fear as a consequence of diabetes that arose during the interviews was the unexpected death of a child, often referred to as 'dead in bed syndrome'. Reports of such deaths on the diabetes online support groups highlighted and made apparent the reality and vulnerabilities that existed. For some members this was distressing and had an emotional impact. When reflecting on any disadvantages of using a diabetes online support group this participant noted:

> *'Sometimes when I read things, like the little boy dying, I think-- sometimes I don't want to hear things like that, I want to shut myself away, and not actually think of the consequences, you know, or ramifications of whatever diabetes can be, in that way it's a disadvantage...because it's actually it opens your eyes to it doesn't it?'* (Participant 9)

Nevertheless, when asked if reading about the death of a child would deter members from using the diabetes online support groups, this participant's response was representative of many others:

> *'No, because God willing, it's few and far between. We all live with that harsh reality, I live with that reality every morning when I go in to _____, you know, in the back of your mind is "is he alive?". That's me being really honest with you, I think a lot of type 1 parents live with that, so we all know, you know, that that's the harsh reality of the condition, really, and it just goes away in its box, but, you know, we're all aware that it's absolutely there all the time.'* (Participant 10)

Whilst sympathy was voiced towards other parents who had suffered a tragic loss, some participants appeared to adopt a more pragmatic approach as a way of dealing with the trauma:

> *'You see the harder stories as well, but I'm of the opinion forewarned is fore-armed, so I do see the harder stories, and we lost a friend's child last week, he's been struggling for a long time... it's horrendously sad, but it also makes you realise that it can happen, and you have to be prepared to deal with it.'* (Participant 2)

Although deaths were not that much of a common occurrence on the online support groups, when they were reported there was a tangible effect on the dynamics and momentum within the group, and a realisation that fear was inexorable:

> *'It turns everybody into a spin, definitely, everybody, the group seems to almost cease trading, you know, it just goes quiet, apart from saying condolences, nobody posts anything else, nobody sort of felt it's appropriate to carry on. Um, and everybody seems to wait for some of us to say... this is just some-- or a general query, "Does anybody know, you know, whether you can get-- is anybody getting x-y-z on prescription?" or something, something really, ordinary, but not general conversation. I think everybody feels really frightened, and it just sort of lays down, just how fragile it all is, really.'* (Participant 6)

> *'All the rationalisation in the world about how rare that is, and how well his condition is managed, and how sensible he is... nothing can stop that fear.'* (Participant 1)

As parents of adolescents with type 1 diabetes, they recognised their child was expected to take greater control of their diabetes management, but participants still had concerns and fears about how their child would deal with their diabetes in the future. Reading posts on the online support groups about the diabetes related issues some adolescents faced when they left home and went to college or university was emotional for some participants. During the interview, this participant became very distressed when she recounted reading messages about a members son who had died whilst at university. The interview was suspended for a time during which she mentioned that reading messages about university 'filled her with dread' as her own son was leaving home in the next few months and she was aware that matters concerning his diabetes management would be out of her control:

> *'That just makes me cry, in fact, I'm crying now. [cries] Actually, I confess, that was one of the things that scared me, one of them at university.... I mean, there's nothing you can do about that, you just*

> *feel terrible, because it's so easily to be where you're at, but again, I think that's one of the powerless things, is there isn't actually much you can do about it, short of not wanting them grow up, and staying by their side the whole time, you know. It's an impossible situation I think, that one.'* (Participant 11)

In spite of this, being able to share these concerns with other members on the online support groups and reading about how other parents dealt with relinquishing control was appreciated by many of the participants, and they reported feeling less isolated during a period of change. Whilst some participants anticipated using the online support groups less frequently as they hoped their child would become more independent, the frustration and fear they felt about the unpredictability of diabetes and the capability of their child meant there was still a requirement at times for practical or emotional support. When asked *"how do you think you will use the boards over the next few years, as he's getting older?", t*his participant responded:

> *'Well, hopefully, it will reduce, because hopefully, he will manage that side of things that-- I think while he's at university.' (Participant 11)*

She then pointed out that she would continue to access the groups to keep in touch with other members and to continue to get information:

> *'Just out of interest to see, you know, how so and so going on, and it's "how's yours getting on and how's mine getting on,"... and you do get quite a lot of tips. You know, the practical tips are quite useful, certainly from the areas where they've got-- seemingly got better care than other areas.'* (Participant 11)

6.4 - Discussion

The present study used a qualitative one-to-one interview method to examine in greater detail the personal online experiences of parents of adolescents with type 1 diabetes who were members of diabetes online support groups.

Influenced by the findings from the first empirical study previously discussed in Chapter 5, this study set out to explore further what motivated parents to join an online support group, and the benefits or otherwise of group membership. This method was advantageous as it provided a means of exploring any new lines of enquiry, whilst giving participants the opportunity to discuss issues salient to them, pertinent to the area under investigation. As a result, the thematic analysis discussed previously, identified five overarching themes: '*It was like a bolt from the blue*' - recalling the diagnosis of type 1 diabetes, '*help I need somebody*' - searching for similar others, '*learning from the experts*' - practical support, *'I get by with a little help from my friends'* - emotional support and *'It's a rational fear' - emotional burdens.* These provide a novel insight into this cohort's perspectives, and will now be considered in the context of the wider literature surrounding health-related online support group use by parents.

The impact of having a child diagnosed with type 1 diabetes was a theme that permeated throughout all the interviews in the current study. It was described as a traumatic life-changing event, and not only for the child. Parents of children with type 1 diabetes have been shown to experience a range of emotions in the period immediately following their child's diagnosis. These can include shock, grief, anger and fear as a number of authoritative qualitative studies have highlighted (Kovacs et al 1985, Lowes, Gregory and Lyne 2005, Wennick and Hallstrom 2007). Additionally, when a diagnosis is delayed, as reported by a number of participants, due to parents or healthcare professionals overlooking or misattributing diabetes symptoms, parents may experience even more negative emotions as reported by Rankin et al (2014). In this qualitative study 54 parents were interviewed to determine their perspectives on the circumstances that led to their child's diabetes diagnosis and their emotional reactions. It was reported either a 'prompt' or 'delayed' pathway to diagnosis had, and continued to have for some, an impact on their emotional state. Parents who considered their child's diagnosis to have been 'delayed' by not recognising the signs of diabetes expressed unresolved and pervasive feelings of guilt. The authors propound that parents' emotional reactions of shock and guilt as a result of their child's diagnosis, offer an insight into why they can become psychologically distressed. This is in line with previous research, which has reported similar findings of higher levels of psychological distress amongst parents of newly diagnosed children (Lowes, Gregory and Lyne 2005, Rankin et al 2014, Streisand et al 2008, Whittemore et al 2012).

For the participants in the current study, it was the traumatic events leading up to a diagnosis of type 1 diabetes for their child and the subsequent consequences of this, which had a motivating effect that led them to search for a diabetes online support group. In keeping with previous research that has investigated online support groups for a variety of conditions, these diabetes specific groups were reported as safe, non-judgemental environments (Attard and Coulson 2012, Mo and Coulson 2014, Sanders et a 2011, Turner 2017). They were populated by other members facing similar challenges and experiences of living with, and co-managing a chronic condition. The benefits for parents or carers of children with chronic conditions of locating 'similar others' online; individuals physically disconnected yet virtually connected via the Internet with a mutual interest in a specific disease, have been reported in the literature for a number of conditions such as cystic fibrosis (Kirk and Milnes 2016), autism (Clifford and Minnes 2013) and kidney disease (Pinsk and Nicholas 2017).

Similarly, there was a sense of homophily as a required characteristic apparent in the interview data with participants when they spoke of the criteria they used when searching for and deciding which diabetes online support group to join. There was a requirement for 'similar others', people who were connected by and had an understanding of diabetes. This sense of similarity was germane and reassuring for participants in the early days of group membership when they were negotiating their way through the online support groups and establishing legitimacy for joining the group (Galegher, Sproull and Kiesler 1998). They described how this was achieved by sharing their child's medical status and the experiences that had brought them to the group. Many of the participants explained they covered this in their first introductory post and were reassured by the welcoming empathetic responses they received, and noted as a salient feature of communication in online support communities (Finn 1999). Participants described how over a period of time as they interacted with other group members, sharing and receiving advice and information, friendships developed they felt comparable to those in the 'real world'. Trusted support networks between members were established based on shared perspectives, beliefs and attitudes indicating that 'value homophily' may be instrumental in establishing trust on online support groups (Wang et al 2008).

Having been motivated to join a diabetes online support group by the diagnosis of a chronic disease, participants in the current study reported they were keen to quickly learn more about diabetes from others who had been through the same experiences (Bender et al 2013, O'Kane et al 2016, Pols 2014). This included finding out about more practical aspects of diabetes management, treatment options and the latest technology such as pumps and insulin delivery systems. The online groups were considered a valuable source of practical information with other parents sharing their experiences, both positive and negative at all times of the day or night. A qualitative study by Greene et al (2011) analysed the content of 690 posts from members of 15 diabetes groups on Facebook and found that information sharing was the most common category (65.7%). Similar findings were reported by White and colleagues (2018) in a larger study. They investigated individuals’ motivations for participating in 'CGM in the Cloud', an online social media community for diabetes created in 2014 with the purpose of sharing information about a DIY mobile technology system for displaying blood glucose values from a continuous glucose monitoring system. Of the 1268 respondents, 79.6% said they would use the online group to learn about the latest technology in diabetes, and over half the respondents, 53.2% said they would use the group to share information about diabetes and/or technology.

The practical information and experiences shared by other members on the diabetes online support groups were valued and considered as credible resources because participants trusted other members who appeared to have similar perspectives and experiences as themselves (Barak, Boniel-Nissim and Suler 2008, Metzger and Flanagin 2013). However, there were some concerns raised about the veracity of information that was sometimes posted on the online support groups and information that was available to search for on the Internet. Websites advertising false cures were mentioned by participants, as well as unsubstantiated fad or potentially dangerous diets as something to be avoided. They gave false hope to members less experienced of dealing with diabetes, and group members who posted details of these were cautioned by other group members or the group moderators, and in extreme circumstances removed from the group. Similarly, offering unsubstantiated medical advice or advocating changes to someone's diabetes management regime was frowned upon and moderated accordingly. In the current study, participants commented that the groups they used were broadly self-policing (Armstrong, Koteyko and Powell 2012), so they were able to access a group consensus and feel more confident that the information and those members sharing it were credible. This was an important aspect of how trust was constructed and negotiated within the diabetes online support groups (Brady, Segar and Sanders 2016).

Nevertheless, some participants reported they were more circumspect with regard to using the diabetes online support groups to help with clinically complex or medical emergency situations. It has been proposed by Gage and Panagakis (2012) that in these situations, fear and anxiety may outweigh the desire to go online for information. Whilst those interviewed said they would access the diabetes online support groups at times when they felt most isolated and alone, such as the early hours of the morning when they were checking their child's glucose levels, because they knew someone else would be online (Shoebotham and Coulson 2016), they still placed higher levels of trust in their child's healthcare team. They would generally defer to the medical advice given from this group above that from other members of the diabetes online support group (Nordfeldt et al 2013). This illustrates how information shared on the diabetes online support groups was framed within the context of experiential information rather than directive medical advice, but if it were felt necessary, group members would encourage others to seek the advice of healthcare professionals (Sillence and Mo 2014).

Whilst participants reported their need for information about diabetes as a significant motivator to join diabetes online support groups (Turner 2017), and exchanging information has been shown to be one of the main forms of support provided by these (Loader et al 2002, Magnezi et al 2015, White et al 2018), the need for emotional support was another motivating factor. For these parents dealing with the pressure of co-managing their child’s diabetes, the psychosocial stressors they faced felt overwhelming at times, and the online support groups provided a safe environment where they felt able to share details of these with other group members without fear of being judged (Gundersen 2011, Ammari and Schoenebeck 2015, Kirk and Milnes 2016). It has been noted by Broom (2005) that discussions within online groups can include a surprising level of disclosure, something that was noted during a number of interviews. Participants revealed they felt more able to share intimate emotional details with other group members, as they had experience of diabetes and understood the pressures more than some family members (Binford Hopf et al 2013). Some described the ability to vent their anger and frustration without reprisal on the diabetes online support groups as cathartic, and they would receive emotionally supportive responses from other members. This was something of particular importance for new group members, especially those who had joined a group immediately after their child's diagnosis when they were facing a shift and re-adjustment in their parental role (Khandan et al 2018). Practical information appertaining to the clinical management of diabetes was given from health care professionals at this early stage, but emotional support was often felt to be lacking. A similar discrepancy was previously highlighted by Rankin and colleagues (2014) investigating parents' information and support needs when their child is first diagnosed with diabetes.

For many participants the emotional support they received from other group members was considered encouraging, gave them a sense of belonging and friendship, and they reported feeling empowered by this (Uden-Kraan et al 2008). As a consequence of being the recipient of emotional support, participants appeared to be more motivated to share their experiences with the group and offered emotional support in an attempt to help others negotiate the complexities of diabetes. This sense of altruistic reciprocity towards others in diabetes online support groups has been described as members 'paying it forward' (White et al 2018).

Whilst there is evidence highlighting the importance of health-related online support groups for parents of children with type 1 diabetes in providing practical information and emotional and social support, negative aspects of group membership have been less well documented. Kirk and Milnes (2016) in a study exploring how young people with cystic fibrosis and their parents use online support groups put forward the case that online support groups have the same potential as face to face support groups to engender negative emotions such as fear, and uncertainty. This was also a theme in the current qualitative study, with interview participants admitting they were fearful at times of reading about the effects of hypoglycaemic episodes and the ultimate fear, the death of a child. This was especially prescient when their son or daughter was away from the home environment, as the participant was not able to control the situation. This has been reported as a major cause of emotional distress for parents (Haugstvedt et al 2011, Robinson et al 2016, Hessler et al 2016, Viaene et al 2017), with particular emphasis paid to psychological distress in mothers, shown as most likely to be the primary caregiver (Jaser, Linksy and Grey 2014) and more likely to access online support groups than fathers.

When negative news was shared on the diabetes online support groups it did appear to have an effect on the dynamics of the group for a period of time. Some members felt they benefited from stepping back from actively posting as a way to deal with the harsh reality of death. Whilst they did not completely leave the group, they 'lurked' until they felt more able to cope or discussions had moved on from the tragic circumstances. Conversely, other members would continue to post details of their experiences to try to maintain a positive outlook, and offer hope to other members. Again, there was a sense of altruism at work within the group, with members doing what they could to help foster a sense of unity (Buchanan and Coulson 2007).

6.4.1 - Limitations of the study

Whilst this study provides an insight and a greater understanding into what motivates parents to use diabetes online support groups, there a number of methodological issues that need to be addressed. Firstly, all the participants interviewed had previously completed the online questionnaire from Study 1. Therefore, they could be considered as highly motivated to take part in research and may represent individuals who are particularly enthusiastic about diabetes online support groups. Secondly, as all the participants were mothers and no fathers were interviewed, this cannot be considered a representative sample. This lack of diversity has previously been acknowledged in analogous research (Balkhi et al 2014, Schroeder et al 2015, Giménez-Pérezet al 2016). Finally, it is important to recognise that this study represents a 'snapshot' of each participants’ perspectives and thoughts at the time of the interview. These are not static, may be liable to change in the future and are open to interpretation (Denzin 2009). Considering these issues, it would presumptuous to suggest that the interview data from the 13 participants could be used to make wider generalisations about how parents of adolescents with type 1 diabetes use diabetes online support groups. However, the data driven analysis of the interviews provides rich qualitative descriptive accounts that captures participants’ perspectives allowing for their individuality.

Chapter 7: Study 3 - Analysis of messages posted on diabetes online support groups for parents

7.1 Introduction

Findings from the two previous empirical studies presented in Chapter 5 and Chapter 6, demonstrate that parents of adolescents with type 1 diabetes access and participate in diabetes online support groups for social support. This was illustrated in Study One where 'emotional support' and 'informational support', were identified from an online questionnaire as empowering processes that occurred in the online groups for parents. Analysis of the qualitative one-to-one interviews carried out for Study Two, identified and categorised social support as 'emotional support' and 'practical support'.

To date, whilst numerous studies have investigated and critiqued how social support has been conveyed to parents of children with diabetes (Hanna and Guthrie 2001, Hansen et al 2012, Lewandowski and Drotar 2007, Seppänen, Kyngas and Nikkonen 1999, Sullivan-Bolyai et al 2010), the emphasis within much of this body of research has been on face-to-face delivery for parents. This is often an impractical or logistically challenging option for parents. As the findings from the two previous studies would indicate, this does not provide the reported benefits diabetes online support groups can, namely access to social support as and when it is needed. Given that diabetes is not a static, but often unpredictable condition, causing parental stress levels to fluctuate in response to external stressors, the need for *'just in time'* social support was demonstrated in the findings to be paramount. These findings are congruent with research that has appraised the online social support needs of parents of children with other chronic health conditions (Binford Hopf et al 2013, Cacioppo et al 2016, Kirk and Milnes 2016, Martin et al 2018, Oprescu et al 2013). Furthermore, research investigating health-related online support groups across a range of conditions (Beck et al 2017, Coulson and Greenwood 2012, Coursaris and Liu 2009, Shavazi et al 2016, Smedley et al 2015) has identified a number of dimensions of social support (Cutrona and

Suhr 1992). This present study seeks to investigate further the dimensions of social support available in online diabetes support groups for parents.

7.1.1 Aim of study

Health-related online support groups as discussed in Chapter 3, have a number of unique characteristics and potential benefits that may provide parents of adolescents with type 1 diabetes with an alternative means of social support. This third empirical study aims to increase our understanding of what types of social support are available by identifying and examining those found in diabetes online support groups for parents over a 5-month period.

Instrumental in the triangulated methodological approach adopted in this thesis, this qualitative study was intended to help establish if phenomenon and themes identified from the previous two empirical studies corroborated with the resultant data; providing a deeper, richer insight and understanding of the role diabetes online support groups have for parents of adolescents whilst improving the validity and rigor of the research (Johnson and Onwuegbuzie 2004, Bishop 2015).

7.2 Methods

Internet forums and online support groups provide a rich source of naturalistic research material, occurring without the presence of a researcher to influence the dialogue and interaction between the forum members (Coulson 2015, Holtz, Kronberger and Wagner 2012). Message postings are unique sources of data, which afford researchers the opportunity to access naturally occurring often spontaneous conversations from hard to reach or under-researched populations (Coulson, Buchanan and Aubeeluck 2007, Elder and Burke 2015, Flower, Bishop and Lewith 2014, Lasker at al 2006). Arguably a less intrusive way of collecting potentially sensitive information (Sixsmith and Murray 2001), the ability to retrospectively search messages posted on online support groups makes it possible to observe how conversations and interactions are created and develop, and by analysis, speculate and interpret for what means. To that end, this method was deemed apposite for the present study, a qualitative exploration of two open-access diabetes online support groups for parents. A deductive thematic analysis of messages posted online over a 5-month period was carried out in accordance with the guidelines set out by Braun and Clarke (2006). The data were analysed using a modified version of Cutrona and Suhr's (1992) Social Support Behaviour Code (SSBC) model as a guiding framework, which allowed for a sizable amount of message posts to be systematically coded and categorised.

7.2.1 Ethical considerations

There has been some debate surrounding the ethical considerations of retrieving qualitative data from online discussion forums for the purpose of research (Bradley and Carter 2012, Jowett 2015). The crux of which appears to hinge on what is deemed public or private online. Online support groups or forums that are by invitation only, require membership or approval from the group moderators to join, are intended to be private. In contrast, it has been put forward that messages posted on online boards or forums accessible by anyone are in the public domain. This line of reasoning arguably negates the requirement of researchers to obtain consent from online contributors, and theorises they are exempt from institutional ethical review (Seale et al 2010). Those opposing this viewpoint, claim that using messages posted online without consent from the posts author constitutes a violation of privacy (Eysenbach and Till 2001, King 1996), and argue even publically accessible posts may be considered as private by those using the group or forum (Elgesem 2002). However, McKee (2013) discussing the ethical challenges faced when defining 'online privacy', argues that with so many people freely sharing images and detailed information about themselves online, determining between public and private can only really be defined by the subjects themselves, 'as they are the authors of their own words'. This issue of public/private distinction online has been addressed in the Ethics Guidelines for Internet-mediated Research issued by the British Psychological

Society (2017), with recommendations researchers should consider when designing and implementing studies using the Internet.

Further concerns regarding the anonymity of the data collected from online forums have been raised. Data from open forums that is reproduced and reported in other mediums such as reports, journal articles and academic thesis may be traceable through search engines (Evans, Elford and Wiggins 2008). In an attempt to mediate for this, it is recommended that forums used for data collection are not named, and the usernames of posters are redacted or pseudonyms used (Bobicev et al 2013, Rodham and Gavin 2006). Paraphrasing verbatim quotations is another option that may be used as a means of reducing the traceability of data to source, and identifying the author (BPS 2017).

In order to take into account and acknowledge the aforementioned ethical issues whilst mitigating for the possible risks of using online support groups for data retrieval, the recommendations set out in the British Psychological Society Ethics Guidelines for Internet-mediated Research (BPS 2017) were closely followed as the principles espoused were considered appropriate for the research paradigm (Smedley and Coulson 2018). As both groups selected did not require membership or a login to read messages on the boards, they could therefore be considered to be in the public domain. In accordance with the British Psychological Society's ethics guidelines for Internet-mediated research:

> “[W]here it is reasonable to argue that there is likely no perception and/or expectation of privacy (or where scientific/social value and/or research validity considerations are deemed to justify undisclosed observation), use of research data without gaining valid consent may be justifiable.” (BPS 2017, pg. 8)

it was not deemed necessary to obtain informed consent from individuals. Nevertheless, ethical approval was obtained from the Faculty of Medical and Health Sciences' Research Ethics Committee at the University of Nottingham (reference N08122015). In order to protect the anonymity of the individuals who had posted messages and to protect the privacy of the groups, all identifying information was removed from quotations used in this thesis (Flicker, Haans and Skinner 2004). Where possible, quotes were paraphrased whilst retaining their meaning, and verbatim quotes were truncated to reduce their traceability through search engines (BPS 2017, Davey et al 2012). The names and web addresses of the online support groups are not included in this thesis.

7.2.2 Data Collection

Diabetes online support groups were identified through the search engine Google, using combinations of the terms 'diabetes', 'type 1 diabetes', 'type 1', 'IDDM', and 'support group', 'forum', 'board', 'message board', 'online support group', 'online support', 'community', and 'parents', 'family', or 'carer'. Only active, publicly available UK based diabetes online support groups were eligible to be included in the study. These were groups where membership or a login was not necessary to view messages, and had a minimum of 50 members with at least 25 messages posted a month (van Uden-Kraan et al 2008, Attard and Coulson 2012). 3 asynchronous diabetes online groups were identified and after careful consideration, 2 were selected for the study. These were chosen due to the high quantity of messages posted and the large number of contributors. Both groups were moderated and provided clear guidelines about acceptable behaviour on the site.

The first group under consideration was accessed via a registered charity diabetes community website with a diabetes support forum that included a 'parents' board'. This was described as an area for parents of children with diabetes to discuss, help and advise each other. The second group in the study was accessed via a private organisation website with an established 'community-profit' culture. This 'parents' board' within the community forum was described as an area for parents for all discussions about caring for children and young people with diabetes and sharing experiences and knowledge. Messages posted on these two diabetes online support groups for parents between November 2015 and April 2016 were collected and amalgamated into one dataset. This was chosen as a means to avoid any comparisons being drawn between the two groups. From this initial dataset, a small number of threads were excluded (n=3). These included threads posted in the wrong forum (identified by the moderators and awaiting relocation), and a duplicated thread (with a request from the forum member requesting moderators delete the duplicate). The final dataset consisted of 102 threads, yielding 945 message postings. The threads were sampled in their entirety, in order that messages could be analysed in context (Sixsmith and Murray 2001).

Each message was copied into a Microsoft Word document (Holtz, Kronberger and Wagner 2012), with the original formatting and layout retained, including textual features such as emoticons and any non-identifying images. At this stage, any further identifying information was removed in order to anonymise the dataset.

7.2.3 Data Analysis

In order to identify and investigate if different types of social support occurred between the members of the online diabetes support groups for parents, the data sample of messages were qualitatively analysed using deductive thematic analysis. Braun and Clarke (2006) have distinguished this from inductive analysis; where the data is coded without attempting to fit it into a pre-existing coding frame or driven by the analytic preconceptions held by the researcher. They propose that conversely, it is the researchers theoretical or analytical point of interest that drives deductive analysis. This may afford a more detailed analysis of a particular aspect of the data, in the case of the current study, types of social support. For that reason, deductive analysis using a pre-existing framework was deemed appropriate, and

Cutrona and Suhr's (1992) Social Support Behaviour Code (SSBC) was chosen and adapted for use.

The authors originally designed the SSBC to assess the frequency of occurrence of face-to-face supportive behaviours between spousal couples, that fall into five main social support categories: (1) informational support (providing factual information, suggestions or advice); (2) emotional support (highlighting love, providing encouragement, communicating sympathy or empathy and understanding); (3) tangible assistance (offering to loan something, perform a task or takeover a responsibility); (4) network support (communicating the availability of, and access to, other persons with similar concerns or experiences); and (5) esteem support (praising other persons abilities, validating their perspectives and alleviating feelings of guilt about an event or situation). Within these five categories are 23 subcategories that allow for a more detailed measure of social support in comparison to other coding frameworks (Braithwaite, Waldron and Finn 1999). The categories and their original definitions are shown in Table 17.

Table 17 - Brief Definitions of Social Support Behaviour Codes from Cutrona and Suhr (1992), p.161

Support type	*Purpose of Communication*
Informational support	
Suggestion/advice	Offers ideas and suggests actions
Referral	Refers the recipient to some other source of help
Situation appraisal	Reassesses or redefines the situation
Teaching	Provides detailed information, facts, or news about the situation or about skills needed to deal with the situation
Emotional support	
Relationship	Stresses the importance of closeness and love in relationship with the recipient
Physical affection	Offers physical contact including hugs, kisses, hand holding, shoulder patting
Confidentiality	Promises to keep the recipient's problem in confidence
Sympathy	Expresses sorrow or regret for the recipient's situation or distress
Listening	Attentive comments as the recipient speaks
Understanding/empathy	Expresses understanding of the situation or discloses a personal situation that communicates understanding
Encouragement	Provide the recipient with hope and confidence
Prayer	Prays with the recipient
Esteem support	
Compliments	Says positive things about the recipient or emphasizes the recipient's abilities
Validation	Express agreement with the recipient's perspective on the situation
Relief of blame	Tries to alleviate the recipient's feelings of guilt about the situation
Network support	
Access	Offers to provide the recipient with access to new companions
Presence	Offers to spend time with person, to be there
Companions	Reminds the recipient of the availability of others who share similar experiences
Tangible aid	
Loan	Offers to lend the recipient something (including money)
Direct task	Offers to perform a task directly related to the stress
Indirect task	Offers to take over one or more of the recipient's other responsibilities while the recipient is under stress
Active participation	Offers to join the recipient in action that reduce the stress
Willingness	Expresses willingness to help

This validated taxonomy, originally designed for the study of support behaviours that occurred in offline environments, has been adapted and employed by multiple researchers conducting qualitative analysis on messages posted in a variety of condition specific online support groups and forums (Braithwaite, Waldron and Finn 1999, Coulson, Buchanan and Aubeeluck 2007, Flickinger et al 2017, Perrone et al 2015, Shavazi et al 2016). Whilst the SSBC has been used effectively to measure the frequency of the five types of social support in these online groups, the focus of the present study was with regard to the types of social support and interactions that took place within the diabetes online communities rather than the frequency with which they occurred. This methodological approach was previously adopted by Coulson and Greenwood (2012) investigating online support groups for families affected by childhood cancer. The authors made a minimal amendment to the SSBC framework, removing the *'listening'* sub-category of emotional support, as it would warrant synchronous interactions not possible in the online environment under consideration. For the purpose of this study, the SSBC with 22 subcategories using the definitions provided by Coulson and Greenwood (2012) was considered apposite as a framework to guide the analysis of the data.

A strategic contingency for messages that could not be categorised into any of the five support codes in the coding framework was devised in line with the recommendations of Braun and Clarke (2006). Such data if identified, would be labelled 'miscellaneous' and analysed using an inductive approach as opposed to being abandoned or discredited. In this way, analysis of the data set was not constrained by the framework (Sandelowski 2010), and this allowed for the exploration of any additional social support themes. Such an approach provides methodological transparency and goes to demonstrate theoretical rigour within this qualitative study (Fereday and Muir-Cochrane 2006).

Initially, a pilot analysis of 20% of the data (20 randomly selected threads, yielding 165 messages) was carried out using this modified SSBC framework to code the messages and determine if any further amendments were required. The results were corroborated by a second independent academic with expertise in qualitative research. Whilst not all 22 subcategories were evident within this data sample, following discussions, it was decided more judicious for the aim of study that no further amendments be made at this stage. This framework was then used to guide all subsequent coding.

For the present study, 102 threads were read in their entirety multiple times to enable this researcher to become familiar with the data. Each individual posting was then coded using the adapted SSBC framework in the context of the originating thread. This allowed for more accurate decisions to be made about which support type was evident. Additionally, non-verbal communications such as emoticons, apparent in some threads, were included in the analysis. These 'smiley faces' located in the text or in some posts, in lieu of text, were used to indicate the emotional state of the member or as surrogates for non-verbal cues such as a tone of voice or facial expressions (Thompson and Fouler 1996). As such, they have been identified as proxies of the 'physical affection' subcategory (Algtewi, Owens and Baker 2015).

As previously noted in this thesis, the process of thematic analysis is not simply a linear format. It is important to recognise that whilst a framework was used to guide the analysis, it is an iterative and reflective process that requires the researcher to be flexible in their approach (Nowell et al 2017).

7.3 Results

In total, 102 threads containing 945 messages from 234 unique senders were coded to identify types of social support using the amended Cutrona and Suhr social support typology. Four of the five categories were observed in the data: information support, emotional support, esteem support and network support. 'Willingness' was the only subcategory of the 'tangible assistance' support category identified during the coding process. Closer examination revealed these messages to reflect a more general willingness to help group members as opposed to a tangible act, and for this reason this subcategory was recoded under *'network support'*. The absence of the 'tangible assistance' support category has been reported in previous studies investigating health-related online support groups (Britt 2017, Huang, Chengalur-Smith and Ran 2014). A feasible explanation is that by virtue of the characteristics of an online community, members are geographically dispersed across a virtual world; hence, the opportunity to meet and provide tangible assistance is rare (Pfeil and Zaphiris 2009). Furthermore, the sub-category *'physical affection'* that included physical contact such as hugging, kissing or hand holding, was changed to *'virtual affection'* as this was considered more appropriate to an online environment (Coulson, Buchanan and Aubeeluck 2007). No additional support themes were identified during analysis of the data. 16 of the 22 subcategories used from the Social Support Behaviour Code (Cutrona and Suhr 1992) were identified in the data and confirmed by a second reviewer. The final classifications are shown in Table 18.

Table 18 - Social support type and associated subcategories identified in posts

Support type	Sub-category	Evident / not evident in postings
Informational Support		
	Advice	Evident
	Referral	Evident
	Situation appraisal	Evident
	Teaching	Evident
Emotional support		
	Relationship	Evident
	Virtual affection	Evident
	Sympathy	Evident
	Understanding/empathy	Evident
	Encouragement	Evident
	Prayer	Not evident
	Confidentiality	Not evident
Esteem support		
	Compliments	Evident
	Validation	Evident
	Relief of blame	Evident
Network support		
	Access	Evident
	Presence	Evident
	Companions	Evident
	Willingness	Evident
Tangible aid		
	Loan	Not evident
	Direct task	Not evident
	Indirect task	Not evident
	Active participation	Not evident

The four types of social support are displayed in the order they were most evident in the data. Whilst it was not the aim of the study to investigate the frequency of support types, it became apparent during the process of analysis that there was a preponderance of certain types of support; namely, informational support and emotional support, followed by esteem support and network support. This observation is not an attempt to quantify the significance of any one support type, nor to suggest a support hierarchy. It is to inform the reader of this phenomenon within this particular dataset, which will be explored in more detail later in this chapter.

The four social support types identified in the diabetes online forums for parents will now be discussed individually with pertinent illustrative extracts from the messages. Where necessary, names, dates and any other potentially identify information will be redacted to protect the anonymity and privacy of forum members.

7.3.1 Sample Characteristics

The sampled threads contained messages posted by individual group members. A total of 210 unique user-names were identified. Demographic data were not available except for that made apparent in the personalised biographical details or user profiles provided by some but not all users. Examination of the messages and any corresponding user profile identified that the majority of messages appeared to be posted by females, with only a small number of users (n=23, 10.9%) identifying themselves as male. However, this number may be greater than reported as some members could possibly prefer to guard their privacy and remain anonymous to others (Brady, Segar and Sanders 2016). Other distinguishing information that was publically viewable was the date the member had first joined the group. What was also made apparent by detailed reading of each thread was that not everyone who posted within the 'parents board' was a parent. For example, some members would reply to, or comment on posts with the identifying caveat

> *'I'm not a parent, but...'*

7.3.2 Informational support

Four subcategories of informational support: advice, referral, situation appraisal and teaching, were observed in the data set.

7.3.2.1 Advice

The subcategory of advice included messages predominantly providing specific advice or suggestions for dealing with the complicated clinical management of type 1 diabetes and the subsequent challenges faced by both parent and child. Informational support was most frequently needed and made apparent when the goal of the support was to solve a problem. For example, group members explicitly expressed their need for information in the first instance by posting threads with self-explanatory titles such as *'Injection problems, help', 'First hypo - advice?, Trying to understand DKA, 'Problems with Accuchek Insight'.* Within the post they would expand on the request, describing their situation and often providing background and clinical context to the request for information. In many instances, the advice posted from other members was based on their own clinical knowledge and expertise, acquired through their personal circumstances and experiences. To illustrate, in response to a member who admitted to feeling overwhelmed by the intricacies involved in managing her child's diabetes and was deeply anxious about carrying out injections, the advice from another member regarding the practicalities of injecting was informative and based on their personal experience as this extract demonstrates:

> *'I have a needle phobia too, so I can relate... I had a 'guide', basically a piece of laminated card with fairly large holes in it to put on thighs when injecting and to spread the sites better.... my last piece of advice: check the length of the needles are right, 12 mm needles go into the muscle and really hurt... the 5-mm do the same job.'*

Similarly, another group member replied to the post and also advised rotating injection sites based on personal experience:

> *'If you inject in the same spot it does sometimes hurt. I choose different spots every time.'*

Other suggestions put forward by group members who had dealt with similar issues involved using distraction techniques or giving out rewards after carrying out procedures:

> *'Reward is good... children with type 1 can get a Rufus bear that has different coloured injection sites (I got one) it really helped.'*

> *'Have you tried linking the injection with some kind of reward or reward chart to save towards a reward?'*

This demonstrates how members were willing to share details of what techniques or strategies had been successful and worked for them, and to discuss how they had coped with stressful situations. Some members shared details of their child's management regime as a means of proffering advice to other group members. As this extract shows, in response to a post asking how to avoid night-time hypos and the best types of insulin to mitigate the risk after a member's son had been hospitalised, another member who had experienced similar issues gave the following advice:

> *'When my son was on Lantus as a basal insulin, we did find that it didn't give the "flat profile" it was supposed to... I just wonder whether this could be the case for your son? Why not see if there's a pattern of higher levels in the late afternoon or if this was a one off due to the school dinner. If due to the action of the Lantus being uneven across the 24 hours, other options your clinic might suggest are splitting the basal into two doses, switching to levemir, or (best option) a pump.'*

Despite the fact many of the advice messages were from members who had dealt with co-managing their child's diabetes for many years, *'I'm an old hand at this'*, and in some cases came from members who identified themselves as having diabetes (both type 1 and type 2) *'I've seen this from both sides'*, advice was often given with the caveat of '*this is what works for us*' reflecting the unpredictable nature of the condition, specific to the individual.

7.3.2.2 Referral

Referral messages posted on the diabetes online group for parents included those directing members to diabetes specific sources of expertise, such as websites and other online resources. This was frequently in response to posts from new members who had a very limited knowledge of diabetes per se and were often unsure what resources were available. Often, it was moderators of the groups who would respond in the first instance and post links to diabetes appropriate sites. Thereafter, other members would echo the recommendation or offer a link to a secondary website or details of another relevant organisation. Additionally, other messages posted were aimed at members who had requested advice about specific logistical aspects relating to diabetes, such as the types of pump available on the NHS, as this reply demonstrates:

> *'That would depend on what is available through your child's diabetes clinic, hospitals have different options on pumps so it's best to check which ones would be on offer to you. However, have a look at INPUT, they offer information, advice and support to those who want to change to pump therapy http://www.inputdiabetes.org.uk/alt-insulin-pumps/'*

There were a number of messages regarding technical problems or concerns with glucose pumps in the data, as this member commented:

> *'I am the mother of a type 1, previously on a Medtronic pump but upgraded to the new Accuchek Insight... a nightmare 6 months with several replacement pumps...the final straw came when the pump appeared to change its own settings and cut off [the] background insulin altogether... hearing about random boluses being delivered etc. is quite scary. Something needs to be done!'*

Another member directed this mother to a specialist board on the forum:

> *'Have a look in the pumping forum, you will find loads of problems. Most have asked for the combi back or changed pump brand.'*

Other members directed her to The Medicines and Healthcare Products Regulatory Agency (MHRA):

> *'You could spend a few minutes on the MHRA website describing the experiences and along with others that are complaining about handsets etc. you could force Accuchek to do a recall.'*

Group members also posted information about disability allowances and how to claim for these benefits with the relevant links. As the example below shows, this parent had posted a message about her teenage daughter's diabetes care plan being ignored by teachers at school to the detriment of her daughter's health. She was finding the situation very stressful and asked what other parents would do in her situation. Another member responded and posted a link to a webpage hosted by diabetes specific website detailing legal information pertinent to issues surrounding diabetes in the school environment:

> *'I read your account and was appalled at the unfair way your daughter was treated. These care plans are meant to inform and prevent discrimination at school for children with diabetes... their actions were non inclusive and caused your daughter to suffer discrimination and possibly ill effects as the result of their ignorance. This may help [website link]'*

Whilst many of the links posted in messages were to official and validated resources such as government run public health websites or well-established diabetes charities, the moderators also drew member's attention to guides or blogs written by other members. Welcoming a new member to the group who described feeling *'terrified and totally out of my depth',* after their child was diagnosed with diabetes, the moderator posted a message with a direct link to a blog post from a long term member:

> *'For you, I would recommend reading [X's] guide for newly diagnosed parents [link removed] which may help you understand the new situation you find yourself in.'*

Other members commented on how this had been a useful resource for them at the start of *'the diabetes journey'*, with one member saying they had read it at 3 am when they were struggling to cope and find anyone who could give them the information they needed.

7.3.2.3 Situation appraisal

Situation appraisal messages were those that helped group members to reassess their situation or circumstances in a more positive manner and were evident in a number of threads. These provided alternative perspectives put forward by others in the group that could go some way to allay their fears about diabetes. For instance, one member posted a message saying she was *'feeling petrified'* and asked for reassurance about dealing with testing her son’s glucose levels throughout the night. She panicked if the readings were too high or low and was upset that this anxiety was transferred to her son. She was reminded, optimistically, that diabetes is a manageable condition and given the following advice by this member who stressed:

> *'Keep calm and don't let diabetes be the focus for your son ... Let him see that you're <u>not</u> panicking (even if you are!) and that it's not the end of the world. It can be controlled.'*

In the same way, another member offered an alternative explanation to calm her fears about why the glucose levels could be fluctuating:

> *'The last thing to remember is that he's a growing boy and that's going to cause a major draw on anything he eats... he probably has a super high metabolism plus he's still developing.'*

What can be interpreted from these data extracts is that situation appraisal helps to redefine, and potentially minimize, the emotional impact of difficult situations related to diabetes. This was also evident when parents shared positive examples of how their child had successfully managed their diabetes, and how this had not stopped them accomplishing things in their life such as going to college, travelling abroad, getting a job. For other parents this was reassuring to read, particularly for those who were struggling with managing or co-managing the complications of diabetes such as fluctuating glucose levels and night time hypos. Likewise, this could be the case for parents with older children with less control over their child's diabetes management. One member posted details about her son who was living away at university, wanted to work abroad in the future but was worried he would not get insurance in the USA. She was apprehensive and confessed to feeling overwhelmed and upset:

> *'all his future plans could be in ruins because of it [diabetes]...his whole life, and possibly, future changed.'*

The reply below from another member whilst somewhat direct, for which the author apologies, is also pragmatic. It attempts to put the original posters concerns into perspective and suggests that being anxious regarding his diabetes falls under the auspices of parenting and it should be treated similarly to how other childhood illnesses were dealt with in general:

> *'Hate to say this luv - but think it's you in danger of being a bit of a drama queen here - he's not a baby now - and he would probably cringe if he read this thread... Oh he'll get insurance OK, it's just the cost of it he won't like but he wouldn't like it anyway with nowt wrong with him! Sorry - but I just wanted to stress that there's no need to stress any more than you would anyway, even if he didn't have diabetes... You just need to take it in your stride, the same, as I'm sure you did with mumps or measles, falling off his bike or out of trees, etc. that he had and did as a kid.'*

When a member voiced their frustration about the negative impact diabetes could have on their child's career after being told by the diabetes nurse specialist (DNS) entry into the armed forces was prohibited, another member corrected the information:

> *'Nurse is wrong, as there are now type 1 airline pilots. Joking apart though what the nurse was trying to do was reassure you that there is no reason on earth that your daughter cannot lead a normal life.'*

Similarly, when a member asked for advice about how to deal with her teenage daughter whose behaviour had drastically changed since diagnosis two years earlier:

> '*Help! I am really struggling with my 16 year old... attitude to everything (me, dad, life in general!) is awful atm... over the past 2 years done a lot of rebellion, telling lies, drinking... she thinks we are too strict... but we don't let her stay all night as we just want her home to make sure that she is safe and well... It kills me inside as I feel like I have lost my beautiful kind loving girl.'*

She was reassured:

> *'It's very common for teenagers to rebel like this...'*
>
> *'The phrase "nobody else's parents are as strict as you" has probably been uttered by every single teenager on the planet!'*

and encouraged by other members with children of a similar age, or who had experienced this conflict within the family to consider the behaviour in the context of 'teenage angst' and advised:

> *'Try not to make it all about diabetes (not saying you are, but your daughter might see it that way, and come to resent her condition).'*

> *'... remember it's a teen thing, not a diabetic thing x'*

7.3.2.4 Teaching

Teaching messages were those that provided factual or technical information that related to diabetes or additionally, dealt with practical or logistical aspects of using the online group. Whilst this type of message was less evident than the other informational support subcategories, a number of posts about advances in diabetes treatment and new equipment were shared within the group to help members increase their level of knowledge and awareness. For example, some posts included links to a particular medical manufacturers website that provided the technical specification sheets for existing insulin pumps or gave details of new models. Other messages provided details of research members had found themselves and felt could be beneficial for others to read. One such example was a post sharing information with a link hosted by a well-regarded diabetes charity website about Robin, an autonomous robot toddler with 'robot diabetes', developed by researchers at the University of Herefordshire. Whilst the stated aim of Robin was to help children improve their confidence and skills in managing their own diabetes, some members were sceptical about the benefits of this research and its efficacy:

> *'The robot is supposed to be a diabetic toddler? ...it can show different blood sugar levels, taking insulin, when to eat etc. I can imagine toddlers being engaged with the concept of it (a robot toy) rather than have an adult telling them things but from what it showed I'm not sure how effective it will be.'*

There was also evidence of messages that were concerned with helping group members navigate the logistics of using the forum to enable them to gain maximum benefit from the group. For example, when a new member apologised for posting the same message twice on the wrong boards, the error was rectified, and other members reassured the original poster:

> *'No worries, [name removed]. Welcome. I see that [moderator] has sorted out your identical posts.'*
> *'Everything in one place now!'*

During the course of a discussion two members wanted to contact each other via a private message (PM) but were experiencing technical difficulties and struggling to understand why:

> *'Hi I've just tried to pm you but for some reason it won't let me! Nope I can't message you either.... I'm on the app but it should still work right?'*

Another member, who apologised for 'hijacking' the original thread, clarified the issue:

> *'I have the answer! Need to make 16 posts before that function is enabled. It's to stop spammers...'*

before sharing a link with the group to a previous thread that gave further information about how to message members privately:

> *'This post explains why.'*

7.3.3 Emotional support

Emotional support was detected through five subcategories: 'relationship', 'virtual affection', 'sympathy', 'understanding/empathy' and 'encouragement'.

7.3.3.1 Relationship

Relationship messages were perceptible in the data, whereby members acknowledged and appreciated the interactions that took place, and noted the importance of closeness and friendship in the online group. This was most apparent in responses to messages from new members, but also extended to infrequent posters or those who said they had 'lurked for a while' before introducing themselves. Moderators and other group members would extend a welcome and share details of the positive benefits of the group:

> *'Welcome to the forum... you are in the right place for support!'*

> *'Hi and welcome to the forum. Ask anything that concerns you and other parents of children with diabetes or Type 1s, many diagnosed as children, will be able to help.'*

This was something that other members seemed to find encouraging, as this reply from a father who was concerned about his child's fluctuating glucose levels seems to confirm:

> *'Thanks guys, seems like here has a strong network of support. It's reassuring to hear that the highs are normal, it's been making me a little worried that we can't bring it down.'*

Similar sentiments were expressed by other members:

> *'I didn't honestly think things would get easier but they are definitely improving, there is loads of support on here.'*

> *'Thanks for the support* 👍 *a muchly appreciated sounding board* 😬

Another member posted a message declaring how grateful she was for having access to the group, *'knowing someone else is up at 'stupid o'clock'* when she was feeling vulnerable and needing support. She was met with the humorous response:

> *'it's what we do here, just us and burglars up at this time in the night'*

7.3.3.2 Virtual affection

The original subcategory of *'physical affection'* was replaced with *'virtual affection'* as this was more suited to analysing the data within the context of an online environment (Coulson et al 2007). Virtual affection demonstrated on the diabetes online boards for parents was conveyed through written text rather than physical contact, with group members sending virtual 'hugs' to each other, sometimes with additional emoticons or emoji's embedded within the post for emphasis. Examples of the verbal affection found in the data included:

> *'I'm sending {{{Hugs}}}'*
>
> *'Big hugs it must be very hard for you xx'*

Replying to an emotional post from another member whose child had been hospitalised after a missed diagnosis of diabetes by their GP, this member verbally expressed their emotions and further emphasised the point by including a kissing emoticon at the end of the message :

> *'Please give her a massive hug from all of us - and - methinks you can do with one yourself!! {{{Hugs}}}* 😘*'*

In some instances, merely a single emoticon or emoji was used by group members responding to posts to express how they were feeling and show their emotions to others in the group. Examples of these found throughout numerous messages and their implied meanings include:

😊 (Happy) 🤗(Hug) 😡 (Angry) 😥 (Sad)

7.3.3.3 Encouragement

Messages of encouragement were exchanged frequently within the group, and there were many instances of positive and encouraging phrases such *'good luck'*, *'well done'*, *'stay strong'*, *'keep calm'* and *'don't panic'* in posts. These were intended to reassure members, provide them with hope and potentially bolster their confidence; not only with regard to the co-management of diabetes but also in the wider context of parenting whilst acknowledging the emotional challenges members were experiencing.

A case in point illustrates this. In a thread started to discuss diabetes management being overseen by teachers in schools, this parent voiced her nervousness about her daughter returning to school for the first time since diagnosis. Disclosing her concerns about her daughter's ability to cope with diabetes outside the home environment, she also went on to share her own emotional feelings:

> *'The school have been fab...but it is so difficult handing over the responsibility... luckily her teacher is trained in diabetes but can't help feeling anxious* 😢 *will be climbing the walls today...'*

Other members put forward positive words of encouragement in an attempt to dispel her worries:

> *'Kids are so resilient... she sounds a smart cookie too.'*
>
> *'...you need to take your strength from your daughter, she probably waltzed off with out a thought !!'*

She later posted an update on the situation thanking the group:

> *'You were right she just breezed in and told everyone what she had to do*👍 *thanks!'*

Sharing the outcome in this way was encouraging for others to read, and gave hope to those in similar circumstances. This type of feedback was something that was actively welcomed by other members, and encouraged by the moderators of the groups who frequently asked:

> *'Keep us up to date with his progress...'*
>
> *'Let us know what happens.'*
>
> 'Keep us informed with your daughter’s progress.'

7.3.3.4 Sympathy

Messages of sympathy expressed sorrow and sadness for the fear and distress the recipient had experienced. Whilst extended for a range of circumstances, they were particularly discernible in responses to new members introductory posts. Often new members would share quite traumatic details of their child's diagnosis and intimate details their own emotional state. Current members of the forum reciprocated by welcoming them to the group, commiserating about the diagnosis and offering sympathy not only to the recipient, but also extending this to their child and family. This was communicated through posts such as:

> *'Welcome, Sorry about your son's diagnosis. Diabetes is hard and it must be difficult for him feeling different from his friends.'*
>
> *'Wanted to say, I am so sorry to read of your little girl's medical problems and I hope the treatment is successful and you can both look forward to a more healthier and a happier future.'*
>
> *'Welcome to the forum, I'm very sorry to hear about the diagnosis... I'm sure you are all feeling pretty overwhelmed at the moment.'*

However, sympathy was not always forthcoming towards the member. In an isolated example, a member posted she was frustrated her newly diagnosed 20 year old son would not use social media groups such as Facebook or online support groups she had identified would be of benefit to him:

> *'I don't want to keep going on about it, but I can't seem to get through to him that it would make it easier to talk with others of a similar age with Type 1.'*

In response, a long term member, who was a mother and had also been diagnosed with diabetes in her 20's, pointed out that online groups were not for everyone, and further distinguished where her sympathies lay:

> *'I have just thought - actually - I don't have a great deal of sympathy for you to be honest - mine is all with your son - cos I know exactly what he's facing.'*

This response caused a number of members to retaliate with posts expressing sympathy towards the recipient regardless of the age of their child:

> *'Now I do have a great deal of sympathy for you...both my children are in their twenties, but I still worry about them. I think it goes with the territory!'*

7.3.3.5 Understanding/empathy

Messages of understanding or empathy were posted towards other members, particularly in response to posts about traumatic or stressful events, such as the initial diagnosis of diabetes, coping with hypoglycaemic episodes, or the logistics of negotiating the application process for social security benefits, such as the Disability Living Allowance (DLA). This type of message was observed frequently in the data, and it was noticeable that the level of personal disclosure shared within posts was high. Members not only shared details of their child's medical history and the current management regime they were assigned to, but also personal details about how they themselves were feeling or coping.

When a father whose child had been recently diagnosed posted he was looking for other families in the same situation as he was feeling *'very stressed'*, this member was quick to reply, sharing additional details of her own recent experiences:

> *'My son was diagnosed 6 weeks ago... I know how you feel, it been a tough time recently. He's on Lantus and Novorapid, so is having 5 injections a day (3 x meals, 1 x snack and 1 Lantus). It was tough in the first few weeks, but kids are amazing at adapting, he's connected that insulin means food and helps with the whole process. Some kids just*

> *won't like it, so maybe worth asking about a pump if that's the case - we are currently looking into getting one for our son.'*

This type of response was typical in many posts, and exemplifies how members would often compare or emphasise the similarity of their own experiences in order to highlight to other members they were not alone; that someone else understood what they were experiencing, and had first hand knowledge of living with diabetes:

> *'We are all in the same boat.'*

> *'... I've been there and got the t-shirt'*

In the following example, a single parent who had previously mentioned having a limited support network, posted late in the evening she was struggling to stabilise her child's glucose levels. She asked for any advice and posted details of the fluctuating readings from the glucose monitor. Other members empathised about the complexity of getting the balance right and shared their experiences as these quotes illustrate:

> *'I can appreciate how difficult and dispiriting it must be at times {{{HUGS}}}'*

> *'My daughter was diagnosed in December and we monitor everything she eats and have noticed any cereal what so ever causes her to go higher than we would like. Hope you get some answers soon, I <u>know</u> how worrying and stressful this is x'*

Messages received from other members that were empathetic or expressed understanding were both appreciated and beneficial. This could be seen in the way the online dialogue developed between members in a thread, with the originating author often thanking others for their responses:

> '*Hi, Thank you so much for your reply and kind words. Xx'*

> *'Thanks for all your replies, am finally seeing a light at the end of the tunnel!!'*

> *'Thanks so much for the link above. Made me think more about how she's feeling and not so much about how I think things should be.'*

7.3.4 Esteem support

All three of the self-esteem subcategories: compliments, validation and relief of blame were present in the data.

7.3.4.1 Compliments

Compliment messages were those that enhanced members' self-esteem by reminding them of their capabilities and their achievements despite the complexity and unpredictability of diabetes. For example, in response to a parent who had previously posted about struggling with his daughter's fluctuating glucose levels, but was now happy to report back to the group they were finally more stable, this member replied:

> *'It's great to hear you are getting your daughters level under control! Well done!'*

Similarly, in a discussion about the importance of monitoring ketone levels, one member described how she had dealt with a particularly high reading of 6.8. Other members praised her prompt response as well as complimenting her parenting skills:

> *'Those ketones were very high, well done you for being so proactive - a supermum!'*

When another member posted about how they were dealing with co-managing the continuous regime of testing and injecting, whilst trying to understand the process of 'carb counting', others applauded her efforts and shared how reading the post made them feel:

> *'That's so good to hear how u are coping! Sounds like u are doing very well with it and the amazing girl is just getting on with it makes me smile!'*

Compliments were typically given when a member shared details of their experiences and had a positive outcome to report. When a member's son had an insulin pump fitted, the family attended a training day and she posted details of how well he had handled everything. She noted that whilst there had been a lot of information to take on board in a short space of time, it was anticipated that a pump would give them all more confidence. Other members appreciated the optimistic post and acknowledged her role in managing her child's diabetes:

> *'Great post. Your son is doing great... ... you deserve some praise too, hope good progress continues.'*

7.3.4.2 Validation

Messages of validation conveyed acknowledgement or agreement with the recipient's feelings and perspectives on the situation related to diabetes. When a member posted about her child's lack of concentration at school and asked if other parents thought this was a consequence of their diabetes, she was reassured this was an issue other parents were aware of by the responses she received:

> *'Hi, when I saw your post I had to respond because I have the exact same issue with my son...He says my favourite word is 'concentration'.... I've never mentioned it to his doctor or diabetic nurse as I've always thought that with a bit of patience, guidance and time he will improve. But as time goes on I do wonder.'*

> *'Hiya, we've had this with my daughter, loses concentration and is getting to the point were she starts to cry and say she stupid.'*

> *'Always had this with my daughter, I really do think even slight fluctuations in bloods, effects the brain.'*

Messages of validation were also appreciated by recipients in response to questions about dealing with the minutiae of diabetes management and the actions required. For example, when a member posted:

> *'I was just wondering how often everyone else checks BG? At the moment I check before eating, two hours after eating, at 8pm when I give levemir (bedtime) and then normally when I head to bed (between 10 and 12). Do you think I could be testing too much? ... I would rather err on the side of caution but just wondering if I need to relax a bit?'*

another parent quickly responded with:

> *'I probably test her roughly the same as you.'*

with further validation of the original posters actions confirmed by the response from this member who wrote:

> *'I'm an adult with Type 1, but the amount of testing sounds sensible to me, I do a similar testing regime and generally test around 7-10 times a day, and occasionally in the middle of the night.'*

Validation was a further reminder to recipients that others understood the situations and issues they were experiencing, and the author of the originating post acknowledged this:

> *'So pleased I joined the forum as good to know our problems are similar to other families.'*

7.3.4.3 Relief of blame

Relief of blame messages were directed towards members who expressed feelings of guilt or culpability over a situation. Under these circumstances, members would post messages attempting to persuade the recipient they were not at fault, and help dissipate their feelings of guilt. This was a sentiment made towards a number of parents who disclosed experiencing these negative emotions after their child had been diagnosed with diabetes. As the following extract demonstrates, this member felt guilty for not recognising the potential symptoms of diabetes in her son:

> *'I somehow feel like I've failed him, especially how he was so thirsty and needing the toilet loads... never in my wildest dreams did I think I was taking him along to the doctors and the nurse was going to tell me his urine test was abnormal.'*

Several members comforted her and reassured her they could relate to the traumatic experiences she and her child had been through:

> '*Don't ever feel guilty - although I still do sometimes - my daughter was also drinking for England and even though I was well aware of the signs of diabetes... I completely missed that one and put it down to her enjoying apple juice too much and being a bit greedy with it!'*
>
> '*My son was diagnosed at 4 and I felt like a terrible failure for a while after that... most of the early signs can be attributed to lots of things... it isn't until they're all presenting that alarm bells ring and you did look for help then, so you did everything right.'*

7.3.5 Network support

Network support messages were observed in terms of four network support subcategories: access, presence, willingness and companions.

7.3.5.1 Access

Access messages offered the recipient connections to other members, with the respondent often acting in an intermediary capacity. For example, members would 'tag' other members they thought would be able to help or offer support into a thread. When one member wrote an emotional and detailed account of his child’s diagnosis, he also disclosed details of his own very recent diagnosis of type 2 diabetes, along with intimate details about the complex relationship he had with his ex partner. A response from one of the group moderators was posted within minutes of his message appearing on the board:

> *'I will tag in a “T1 mum” who is also a T1 herself [forum member name removed], I'll tag in [forum member name removed] who knows her onions too... ... you may need some T2 input for your good self? I'll tag in [forum member name removed]... ... hopefully this will get the ball rolling for you and your kid.'*

Occasionally members would tag other members into threads they thought might be of interest or beneficial to them, connecting them with other members. In a discussion about moving from insulin injections to an insulin pump the author of the thread tagged in another member who they noticed had asked in a previous thread for information about this subject:

> *'[name deleted] just tagging you in as you asked for feedback.'*

7.3.5.2 Presence

Presence messages provided support by reminding members that the online group acted as a network to provide continuous support, and that no one should have to struggle alone as there is always *'someone there'* for them. This type of support was typically offered as a response to introductory posts from new members. For example, when a member introduced themselves to the group asking for '*some moral support initially*', and explaining she felt *'devastated'* by her son's recent diagnosis, she received the following replies:

> *'A warm welcome to the forum, I'm glad you have found us. Do let us know how you are all getting on.'*
>
> *'There are loads of great people here with loads of experience so don't be afraid to keep the forum warm it helps to talk to people who*

> *understand.'*

Additionally, members would sometimes follow up on posts asking the recipient for an update on an issue or situation they had previously shared, and encouraging them to keep the group informed. This was the case when a member started a discussion about her experiences of her son being diagnosed with diabetes and concluded with:

> *'It's good to be able to get it all off my chest... thanks for reading. I'm looking forward to being part of this community xx'*

In response, this member replied:

> *'Keep us up to date with his progress, and there will be lots of people here happy to help with any questions.'*

A similar message was posted in response to member who had asked the group for information about how to distinguish DKA from the more typical signs of diabetes, as she was concerned about her daughter’s high glucose levels:

> *'Keep in touch with us and let us know how your daughter gets on.'*

Messages such as these help emphasise the communal nature of the group and can be considered important indicators of presence.

7.3.5.3 Willingness

Willingness messages conveyed offers of help that were generally non-specific but well intentioned towards the recipient, as the following quote demonstrates. In response to a member who mentioned they were nervous, as they had volunteered to speak about diabetes at a school assembly, this was posted:

> *'I am not a public speaker but am very willing to help if I can?'*

7.3.5.4 Companions

Companion messages served to remind members they were not alone, that there were others in the group who shared similar interests and experiences. Not only did these communicate and emphasise the presence of other members, but they also showed friendship. This was demonstrated in messages whereby members would offer to communicate with the recipient in a more private manner, away from the board. For example, when a member posted she was struggling to deal with the physical effects managing her son's diabetes was having on her:

> *'I am exhausted checking his bg at 3-4am every night then can't get back to sleep but I am paranoid he has a nocturnal hypo. I need help, tips of any kind.'*

she received a message from another member attesting to the support offered by the group and also extending a more personal invitation to her:

> *'I have found this forum to be very supportive and if I can be of any help then please don't hesitate to message me :) '*

Similarly, responding to a member's question about how to treat his daughters waking hypo, a long-term member offered:

> *'Have you spoken to many diabetic people in person or say on the phone? If you want to drop me a telephone call.... then private message me for my number.'*

7.4 Discussion

The aim of this study was identify, describe and illustrate the types of social support offered within diabetes online support groups for parents of children with type 1 diabetes. Using deductive thematic analysis, guided by the Social Support Behaviour Coding framework (SSBC) (Cutrona and Suhr 1992), four types of social support were identified: informational support, emotional support, esteem support and network support.

During analysis of the messages from the parents’ diabetes online support groups, informational and emotional support messages appeared to be those found more often in the dataset. Whilst a speculative observation, as it was not within the scope of the study to quantify the incidence of message types, previous research investigating online support group use by parents of children with chronic health conditions has reported parents accessing these online communities predominantly for this type of support (Glenn 2015, Niela-Vilén et al 2014, Paterson et al 2013). Likewise, this incidental finding was commensurate with other studies utilising Cutrona and Suhr's five category taxonomy (1992) to examine support in health-related online support groups (Britt 2017, Coulson and Greenwood 2012, Coursaris and Liu 2009, Roffeei, Abdullah and Basra 2015) where informational and emotional support were most frequently noted.

Whilst the original aim of this study was ostensibly to identify the types of support found in diabetes online support groups for parents, this secondary observation could be explained apropos of Cutrona and Russell's (1990) optimal matching theory. This indicates that controllability of stressors is the key variable in determining the type of support required, with controllable events requiring more informational and tangible support, and uncontrollable events requiring more emotional support. As previously noted, tangible support was not identified in the data, but the findings of the present study indicate that the majority of the support provided in the diabetes online support groups constitutes an optimal match for the support needs. Controllable events such as managing the clinical or logistical aspects of diabetes were met with informational support from members on the diabetes online support groups, and uncontrollable events such as the traumatic diagnosis of diabetes were similarly afforded more emotional support.

Informational support was evident in many of the messages from the parents’ diabetes online support groups, frequently in the guise of advice from members providing factual or technical information, such as details about new insulin pumps or glucose monitors that were being made available. Parents were able to use this as a means to be better informed and develop a greater understanding about various aspects of living with diabetes, particularly those related to clinical management and issues surrounding the logistics of welfare entitlements and legal rights. Given the often capricious nature of diabetes, that can have life threatening consequences for the individual (Anderzén et al 2016, Brink 2014, Lind et al 2014) receiving or reading messages within the online group that gave specific or detailed information was shown to be particularly beneficial for new members asking for help. In these circumstances, parents often reported a limited knowledge of diabetes; which extended to the long-term prognosis, as well as fear and insecurity about their own ability to cope with the demands of managing a chronic condition.

This insecurity has been shown to lead to a range of associated psychological disorders for parents, including anxiety, stress or depression (Nicholas, Gutwin and Paterson 2013), all recognised as factors which can influence or motivate parents to seek online access to information and support. Often, in response to posts requesting help, existing group members would provide detailed medical and clinical information appertaining to diabetes, before sharing personal information about their own child's diabetes management regime. This appeared to not only be a means to corroborate or validate the information they were promoting, but also to further establish their role and veracity as a valued member of the group. Recipients responding to these types of messages would often express gratitude and relief. It is therefore feasible to speculate that as a consequence of the informational support found on the diabetes online support groups a number of positive outcomes for parents are possible. For example, increased parental diabetes knowledge has been linked to better glycaemic control in their children (Al-Odayani et al 2013, Mahfouz et al 2018), which in turn has been shown to reduce levels of anxiety or distress in parents (Maas-van Schaaijk, Roeleveld-Versteegh and van Baar 2013). Moreover, in the present study, having access to information from online group members demonstrating a higher homogeneity of diabetes knowledge and experiences than other 'offline' social networks such as friends or family was beneficial. This appeared to help manage or alleviate the anxieties less knowledgeable members demonstrated in their originating posts.

Analysis of the message posts in the data set showed that informational support was offered to parents of children of differing ages and different developmental stages, which presents different challenges for parents. Parents would give details about their child's age when they posted a question or asked for information. Members who were parents of younger children were in receipt of informational support that helped them deal with highly medicalised and emotionally charged aspects of diabetes management, such as carrying out insulin injections and testing glucose levels. In contrast to members who were parents of adolescents and young adults, where the emphasis on informational support in messages was more to aid them facilitate their child to become more autonomous in their diabetes management. Consistent with the chronic nature of diabetes, the need for informational support continues to be required by parents on the diabetes online groups as their child grows older, but evolves accordingly (Holtslander et al 2012).

This was particularly germane for parents who were no longer responsible for their child's diabetes management but continued to use the online support groups as they still wanted this action facilitating type of support and continued to find it beneficial, a point similarly noted by Ravert and colleagues (2015). Whilst this may seem somewhat idiosyncratic, it highlighted the diversity between members in the group and their roles within the online community. Furthermore, it also recognized the scope and breadth of knowledge and personal experience that continued to be available in one place at any one time, in contrast to offline face-to-face support groups (Pinsk and Nicholas 2017). This was seen as a major benefit of the diabetes online support groups for parents, particularly when members were desperately in need of information quickly or at an inconvenient time such as the early hours of the morning (Balkhi et al 2014, Gavrila et al 2019).

However, it is salient to note that informational support within online health groups is not without issues regarding trust and expertise (Sillence 2017). Whilst some of the information put forward by group members was in the form of links to established and certified clinical websites such as those run by the NHS, there were occasions when members shared information or details of websites where the clinical credentials were less well defined, warranting further scrutiny or investigation. In these circumstances, establishing the validity or trustworthiness of the information posted online became more difficult. Whilst high levels of trust regarding information received has been reported in a small number of online diabetes communities (Balkhi et al 2014, White et al 2018), the potential exists for biased or even low quality information to be posted by group members. Given the potentially catastrophic consequences of misinformation relating to clinical matters, such as adjusting insulin dosages, the group moderators were vocal and active about removing links or information they deemed inappropriate. Similarly, members would post information with caveats such as *'this is what we use'* or *'this is what I do'.* Despite this, the ultimate responsibility lay with the individual member to process and assess the information accordingly, before deciding if they trusted the generating source and utilising it. Whilst recipients were seen to express gratitude for messages of informational support, evidentiary they had read the message, it was not possible to identify with any certainty the uptake of the information; how or if the recipient used it, and any ensuing outcomes, beneficial or otherwise.

For many parents, emotional support appeared to be an integral function of the diabetes online support group as it was found to be highly prevalent throughout the dataset of messages. Sympathy was often extended during welcome messages to new members, many of whom had shared details about what had brought them to the group in the first instance, most typically a diagnosis of diabetes. In response, other members would reciprocate by sharing details of their own experiences, often explaining why they had joined the group, the benefits they had gained and encouraging 'newbie's' to take 'join in'. This was reassuring for recipients to read, many of whom had described their experiences of diabetes and current emotional state in negative or pejorative terms. Whilst this type of support has been considered to reduce the intensity of negative emotions (Cutrona and Suhr 1992), in the context of parents using diabetes online support groups this positive outcome appeared to be a motivating factor that encouraged members to remain in the group, to participate in discussions, and in doing so go on to provide various types of support to others.

When examining the emotional support that occurred on the diabetes online support groups for parents, a high level of personal disclosure was conspicuous in some messages. Members disclosed exceedingly personal and intimate information about themselves. They shared details regarding their own health, personal relationships and emotional status, and this was evident in posts from both male and female members. This disclosure also extended to sharing personal details of members’ children, including names, ages, medical details, and sometimes photographs. This raises some interesting questions about parents’ stewardship of their child’s privacy within the online support groups, particularly if members are posting personal, often confidential details because they conceive themselves to be in 'safe' or 'closed' online community. It has been argued that parents may be inadvertently compromising the privacy of their children by over-sharing on social networks such as Facebook and Instagram (Minkus, Liu and Ross 2015), and should be more vigilant about how they manage their children's identities online (Ammari et al 2015). To date there appears to be scant evidence of this being researched with regards to health-related online support groups for parents.

However, similar to the issues previously noted surrounding the trustworthiness of information found on the online groups, it should also be considered that individuals posting messages may not be genuine with regard to the online persona they present to the group, i.e. introducing themselves as a parent or carer of a child with diabetes. They may have created or adopted a character to enable them to join the group, describing fabricated situations and experiences in order to engage with others for a variety of reasons. These may be legitimate and benign (Bowker and Tuffin 2006) or conversely, deceptive. There is evidence to inform this relatively novel phenomenon, termed 'Munchausen by Internet' (Feldman 2000), of individuals portraying themselves on online parenting forums as the mother of a sick child (Lawlor and Kirakowski 2017). This type of targeted deception can not only undermine the integrity of an online support group (Dahlberg 2001) but can also leave respondents who were unwittingly duped into engaging into communication feeling angry, manipulated and violated (Lawlor and Kirakowski 2017). In response, members may be distrustful or sceptical of other members, or no longer feel motivated to participate in the online group and choose to leave.

Taking this into account, and given the high levels of disclosure by parents in the present study, it would be fair to assume that many members had a sense of trust about whom they were sharing their details with. One explanation for this level of disclosure would be that the online groups were considered a *'safe and secure environment'* (Caplan and Turner 2007) whereby members felt able to share such highly personal and intimate details in a non-judgemental environment. Furthermore, it has been shown that members of online support groups trust those who demonstrate similar experiences and perspectives to themselves (Brady, Segar and Sanders 2016). As mentioned, such reciprocity of exchanging similar experiences was in evidence on the diabetes online support groups, and this has been a prominent feature reported across other health-related online groups for parents of children with long term or chronic illnesses (Coulson and Greenwood 2012, Cacioppo et al 2016, Glen 2015, Kirk and Milnes 2016, Navarro et al 2018).

Further inspection of the message postings from the dataset collected for the present study showed that whilst messages of sympathy were directed in the main towards new members, often in response to an introductory post, empathetic messages appeared to be more distinguishable between members of a longer standing within the group. In certain discussion threads there was an apparency of existing relationship between members; an acknowledged community history, with references to previous online discussions, past events or the tagging of other members in posts to illustrate a point. Again, as a means of offering emotional support, these empathetic messages continued to exhibit high levels of personal disclosure, with group members letting the recipient know they understood what they were going through, supporting this sentiment with examples of their own experiences (Pfeil and Zaphiris 2007). This also served to give members a sense of being connected to a virtual community that could be *felt,* and was perceived as a warm and welcoming community (Hargreaves at al 2018). For parents living with diabetes, being aware of the issues and potential complications their child could face during different life stages was stressful, but knowing that other parents had dealt with and could empathise about these often distressing events, provided emotional support. Empathic messages were often seen to contain expressions of encouragement towards the recipient. For some members, this helped mitigate the fear and distressing emotions they described having experienced when their child was first diagnosed, and for others it gave reassurance and hope for the future when they knew they had contact with other people who understood their concerns.

In addition to the informational and emotional support offered to group members, esteem support and network support were also evident in the diabetes online support groups. In the context of Cutrona and Russell's (1990) optimal matching theory, esteem support is deemed valuable for both controllable and uncontrollable stressors or events. Messages exhibiting esteem support served to validate the views and perceptions of group members by expressing agreement and signalling a commonalty of experiences and shared understanding with the recipient. For parents experiencing feelings of guilt and emotional distress about their child's diabetes (Bowes et al 2009, Rankin et al 2014), esteem support was often provided by the relief of blame; messages assuring members they were not at fault for their child’s health condition, which many found comforting. A further function of esteem support was the positive assessment extended towards other members by way of complimenting or congratulating them on their ability to cope with stressful situations such as hypo's or logistical issues associated with diabetes, and the subsequent outcomes. Other group members, not only the recipient, found this type of support beneficial. Reading about other members’ positive experiences of managing fluctuating glucose levels during the night and 'success stories’ (e.g. being granted Disability Living Allowance (DLA) or Personal Independence Payment (PIP)) not only reassured parents about what they were doing and how they were coping, but was also a source of inspiration for some. Positive outcomes such as these were something many members aspired to, and reading about this in posts increased recipients confidence in their ability to improve their own situation or circumstances. As an observation, esteem support in the present study was in many instances woven throughout messages containing other types of support on the online support groups, particularly in relation to informational and emotional support, which draws attention to the notion of overlap between differing support types and functions.

Messages from group members provided network support by reminding recipients they were not alone but in the company of other members who understood their circumstances. This type of support may have promoted the group not only as a venue, but also a community where there was the opportunity to interact with other people who had similar experiences and an appreciation about living on daily basis with a chronic disease (Britt 2017, Coulson, Buchanan and Aubeeluck 2007, Smedley at al 2015). This type of support was often extended towards new members by more experienced members of the group, identified as such by the nature of their comments and the information they shared. It was beneficial for these recipients who could feel isolated from friends and other family members due to their minimal understanding of diabetes care (Smaldone and Ritholz 2011). In this way, network support helped promoted a higher homogeneity of experience and understanding about being a parent of a child with diabetes than some other 'offline' social networks.

The final category, tangible support was not identified in the dataset of the present study. Previously explained by the absence of physical proximity between members, a further consideration is that due to the management characteristics of type 1 diabetes i.e. subcutaneous injections of a prescription only drug, the opportunity for group members to offer loans to others was not only limited but actively prohibited by the group moderators. This finding would indicate that tangible support as defined by Cutrona and Suhr’s SSBC framework (1992) might not be applicable or best suited to the cohort under investigation, an online community, and would benefit from further investigation and potential modification.

7.4.1 Limitations of the study

This study contributes to the knowledge and understanding regarding the types of support available to parents of children with type 1 diabetes using diabetes online support groups. Use of a pre-validated theoretical coding framework of social support, successfully used to analyse online messages for a range of health conditions, has increased the reliability of the data analysis. Furthermore, this ensured the support categories were well defined and further safeguarded against the possibility of unintentional drift during the coding process and categorisation of support types in the messages from the dataset.

There were a number of limitations of the present study. The relatively small sample size of 102 distinct threads containing 945 messages obtained from two publically accessible diabetes online support groups for parents, meant that the extent to which the results are generalizable with regard to other online diabetes communities is unclear, and should therefore be treated cautiously. The findings may be particular to the members of these diabetes online support groups and it would be unwise to generalise with any certainty beyond the sample.

A second consideration is that of the strategy used for selecting messages for analysis. For practical and logistical reasons messages from a 5-month period were selected from two diabetes online support groups for parents. Whilst this is a moderate timescale, the findings indicated that 4 types of social support were consistently coded within this dataset, with all messages exhibiting at least one or more types. Therefore, it would seem unlikely that increasing the period from 5 months and consequently increasing the number of messages would have had changed the social support types identified.

Thirdly, whilst potentially 210 group members were identified in the data by way of a unique user name, it was not possible to corroborate that one individual corresponded with just one username. Furthermore, the demographic information that was available regarding members was scant and often inconclusive. Only limited information regarding age, gender and their interest/association to diabetes could be gleaned from a member's limited biography under their user profile. Whilst further information was often made apparent in member's posts, such as the age of their child and the length of time since their diagnosis, this again was unsubstantiated. This raises questions about the representativeness of members, as there was evidence in a small number of posts to suggest that not all those using the online groups were actually parents of a child with diabetes. Whilst the anonymity afforded by the online support groups was potentially a contributing factor to the levels of personal disclosure exhibited by members, it simultaneously prevented a comprehensive exploration of the types and demographics of users.

A further observation from the findings of the present study related to differences between the numbers of times an originating thread was read and the number of replies it received from members. For example, a thread started by a parent about injection anxiety received six replies from other members offering advice and providing information, but was viewed over 500 times. Likewise, a thread about a member’s university student son being diagnosed with diabetes received eleven messages containing various types of support and was viewed over 900 times. Similar discrepancies were found throughout the dataset, and whilst not within the remit of the current study to explore this finding in any great detail, it would suggest that some members may 'lurk' within the online support groups; choosing to observe discussions and interactions between other group members rather than contributing to a thread (Edelmann 2013). This may be because some do not feel the need to post a message or respond to a post because they acquire what they need from other members contributions; be that information, advice, validation or emotional support.

Alternatively, ‘lurking’ within the diabetes online support groups could be related to the levels and development of trust and distrust within the group (Radin 2006). Some members will immediately post messages and interact with the group, others may be more circumspect, observing how discussions develop and taking time to consider if they find the information and support offered trustworthy. This may motivate them to move from lurking to more active participation. Whilst members who lurk have been shown to obtain substantial positive benefits from accessing health-related online support groups (Merry and Simon 2012, Petrovčič and Petrič 2014), more active members, more visibly engaged with the group may gain greater benefits (Ziebland and Wyke 2012) including social support and more satisfaction with other members (Mo and Coulson 2010). Further research would be required to fully investigate this unexpected observation, exploring the development of trust between members on an online support group where clinical information is often required, highly valued and frequently exchanged.

7.5 Conclusion

Diabetes online support groups for parents appear to offer four major distinguishable types of support to members: informational, emotional, esteem and network. In contrast to face-to-face support groups, support is issued in response to written messages, directed towards members sharing personal details and experiences **with** the group, or asking for information and help **from** the group. The predominance of Informational and emotional support in the current study is consistent with previous research examining social support for other chronic and long-term health conditions, lending support and validity to these studies. Furthermore, this provides textual evidence that the support offered by group members is an attempt to match the support needs of actively participating members. A further hypothesis from the findings is that non-participatory members, 'lurkers' may also vicariously benefit from different types of support by observing discussions and interactions on the online support groups.

Chapter 8: Discussion

8.1 Overview

The overall aim of this thesis was to explore how and why parents of children in mid to late adolescence with type 1 diabetes in the UK chose to use diabetes online support groups. The research sought to investigate if parents found the experience of using these online groups empowering, and if group membership afforded any positive psychological benefits in relation to diabetes distress.

The three empirical studies presented in Chapters 5, 6 and 7 as part of a mixed methods research design provide an original insight into the role of diabetes online support groups for parents affected by, or managing, their child's diabetes care. Adopting this triangulated approach and coalescing the results from each study not only serves to meet the individual research aims of the thesis, but also provides a deeper understanding of issues pertinent to the use of diabetes online support groups by parents. The results from these complementary studies address a gap in the literature with regard to how these novel diabetes online communities provide social support for parents and the implications and benefits this can have on the psychological well-being of a previously under-researched cohort.

This chapter draws together the findings of the three empirical studies and discusses them in relation to the original research aims, and within the context of the existing literature appertaining to diabetes and online support groups. Methodological issues associated with the current research will be discussed, followed by recommendations for further research.

8.2 What motivates parents to use diabetes online support groups?

As the literature reviewed in Chapter 3 suggests, online support groups provide a community whose unique characteristics make them an appropriate medium to address the support needs of parents co-managing the diabetes care of a child with type 1 diabetes. Whilst there is increasing evidence of the potential advantages and subsequent benefits of online support groups for parents of children with chronic health conditions (Baum 2004, Balkhi et al 2014, Cacioppo et al 2016, Han and Belcher 2001, Kirk and Milnes 2016, Stewart et al 2011), there is limited research regarding the motivations of parents affected by diabetes for accessing these. Findings from the three empirical studies address this gap in the literature; providing new information and perspectives on what motivates parents to access diabetes online support communities. The findings provide an insight into what parents' expectations of the online diabetes support groups are, and if they believe these are met.

Analysis of the qualitative data from the three studies found that it was common for the initial diagnosis of type 1 diabetes to have a motivating effect, which led parents to use the Internet to search for an online group or community that could address their current needs. This perceived change to their child's health status served as an initiating factor for online support group use by parents in the current study, a concept introduced in LaCoursiere's (2001) theory of online social support.

Congruent with findings from the endocrinology, nursing and health psychology literature, reactions reported by participants in Study 2 to receiving their child's diabetes diagnosis were those of shock, grief, anger and fear (Bowes et al 2009, Lowes, Gregory and Lyne 2005, Rankin et al 2014, Streisand et al 2008). Furthermore, a sense of guilt was noted. This often stemmed from a lack of knowledge about the aetiology of diabetes, causing some parents to query if they were responsible for their child's diabetes due to something they had inadvertently done. This echoes findings from a study by Seppänen, Kyngas and Nikkonen (1999) who reported mothers had strong feelings of guilt for the loss of their healthy child following a diagnosis of diabetes. As the primary caregiver they perceived themselves to have failed their child and assigned themselves blame (Bowes et al 2009, Cavini et al 2016).

Correspondingly, the literature around chronic illness suggests feelings of guilt can be triggered or intensified during social interactions with people unfamiliar with the condition, leading to a sense of stigmatization (Charmaz 2009). Parents who have gone through the difficult experience of having a child diagnosed with diabetes can feel socially and emotionally isolated due to a lack of support and understanding in their existing social network. This is a key motivator for joining a diabetes online support group in that it provides a means of access to 'similar others'. These are remote, yet electronically connected individuals who not only have an understanding and experience of the clinical logistics of diabetes, but also appreciate the emotional effect this can have on a parent and the repercussions thereof.

The collective results from the three empirical studies provide further evidence that supports this notion of parents wanting to feel connected with others who understood and were able to empathise about the varied aspects of living with diabetes. Findings from the open-ended questions included in the Study 1 online questionnaire suggest that parents value the sense of community within the online groups, and this was a sentiment that resonated across the interviews carried out for Study 2. Recognising similarities with other group members and their shared experiences had a positive effect for parents. It reassured them they were not, as many had previously felt, *'the only one'* coping with a child with a chronic condition. Being aware that other people had an understanding of what they were going through and could offer help and advice based on their own real-life experiences helped alleviate feelings of isolation and loneliness.

Interestingly, this was similar to the responses from participants in a study carried out by Smaldone and Ritholz (2011) investigating the experiences of parenting children with diabetes. The authors reported parents felt comfortable sharing their experiences with other parents in a face-to-face diabetes support group and consequently described feeling less alone after participating in the group. Whilst this study, along with other previous research, demonstrates the long espoused benefits of traditional face-to-face support groups for parents of children with type 1 diabetes (Creedy et al 2005, Streisand et al 2008, Wennick and Hallstrom 2007), it has been established they are not always a convenient option for parents to attend due to time or location restrictions. Given that diabetes is by no means a static disease, online support groups have the added advantage of being more accessible to the individual as and when they are required due to their asynchronous nature. Data from the present study showed that group members appreciated this feature of online support groups. For parents of a child with diabetes, an often unstable condition requiring precise reactive treatment, the ability to access a support network 24/7 was not only viewed as reassuring, but potentially life-saving. It gave them the means and opportunity to seek out people who could understand their situation due to having similar experiences.

In keeping with findings from previous studies that have explored engagement with diabetes online groups (Balkhi et al 2014, Green et al 2011, Schroeder et al 2015), parents in Study 1 and Study 2 considered the online support groups they accessed as important repositories of diabetes-related information. Further analysis of these data revealed that information from the online groups was considered supplementary and complimentary to the clinical information and medical advice that came from health professionals. In essence, this stemmed from, and was underpinned by, the experiential knowledge or expertise of other group members. This helped establish the intent of members and the information posted as trustworthy. Similar findings were evident in a recent study by Rafferty, Hutton and Heller (2019) who found that parents of children with chronic conditions (including diabetes) trusted other parents online to offer practical and helpful advice based upon their first-hand experience. Being able to access information that was not only factual but also deemed credible (by merit of parallels being drawn between personal experiences) was identified as a primary motivation by almost all the respondents in Study 1, and reinforced by the qualitative data from Study 2.

8.2.1 Are mothers more motivated than fathers?

An aim of this thesis was to explore what motivates parents to use diabetes online support groups, thus it is worth reflecting on a notable discrepancy that was identified between the participant characteristics, namely gender. The overwhelming response to the online questionnaire conducted for Study 1 was from participants who identified themselves as mothers (n=87), with only 1 father completing the survey. For Study 2, no fathers were interviewed. Similarly, analysis of the user profiles in Study 3 revealed only 10% of group members were potentially identifiable as fathers.

Several possible explanations could account for this gender discrepancy between parents across the three data sets. A Pew report found that whereas 'women and men are equally likely to have access to the Internet... women are more likely than men to report gathering health information online’ (Fox and Duggan 2013 pg. 13). This mirrors findings from research carried out by Stern, Cotten and Drentea (2012) exploring the influence of gender and parental status on how people search for health information online. Here the authors found mothers were not only more likely than fathers to search for health information for other people online, but were also more inclined to use that information when making health-related decisions. This reinforces the notion of women and mothers as the 'gatekeeper' for their family's health (Warner and Procaccino 2007).

As discussed in Chapter 5, mothers have been identified as the primary caregivers of children with type 1 diabetes, and report higher levels of stress and diabetes distress than fathers (Hansen et al 2012, Haugsvedt et al 2011, Nieuwesteeg et al 2017). Because of this, mothers may be more incentivised to use online support groups as a means to reduce or alleviate these emotions. Findings from the present study would support this. Interview data from Study 2 revealed that whilst participants were initially motivated to join diabetes online support groups to obtain practical and logistical information about diabetes management, they recognised they were also actively looking for some emotional support. This was important for parents who reported feeling marginalised by friends, family and in certain instances health professionals. The diabetes online support groups provided them with the opportunity to share their perceptions and emotional reactions towards their child's diabetes in a safe environment. Here, these could be validated by other empathetic members, helping to negate emotional distress and manage offline frustrations. This has been considered a beneficial aspect of online support groups, particularly of note for communities where the somatic nature of the condition is contested or there is a lack of visual cues, as with type 1 diabetes (Chen 2012, O'Kane et al 2016).

As discussed above, the initial motivation for parents to join a diabetes online support group was explained by the impetus of a challenging event. Results from Study 1 showed the average time since diagnosis was 6.5 years (SD 3.95) with participants presently demonstrating a personal understanding of the disease, a positive belief in the effectiveness of the prescribed treatment and their ability to co-manage this. Participants interviewed for Study 2 attributed this to the diabetes information and support given to them by other members when they first joined the online groups. The timing, speed and accuracy of information they received were cited as motivations to remain in the group during a period when they were expected to negotiate a steep learning curve regarding diabetes. Nevertheless, it is interesting that levels of engagement, ascertained by how often parents visited the online groups, remain high. Over 80% of participants reported visiting their chosen support group at least once a day, and 10% several times a week. It was therefore judicious to broaden the scope of the original question, and consider what it is that continues to motivate parents to use diabetes online support groups during the different phases of the disease trajectory, and their child’s development into and beyond adolescence.

Returning to the results presented in Chapters 5, 6 and 7, the findings showed that diabetes online support groups acted as a tool of empowerment for participants. Further analysis revealed this had a positive impact on parental intention to continue using the diabetes online support groups, and will be addressed in the next section.

8.3 Empowerment online

Results presented in Chapter 5 from Study 1 identified empowering processes and outcomes consistent with those from previous research using the empowerment framework developed by van Uden-Kraan and colleagues (Aardoom et al 2014, Bartlett and Coulson 2011, Campbell, Coulson and Buchanan 2013, van Berkel, Lambooij and Hegger 2015, van Uden-Kraan et al 2009). Whilst these past studies were undertaken within online support groups used primarily by individuals who identified as having a particular condition or disease, the current research extends the previous findings. It contributes to, and augments the extant knowledge regarding the empowering potential of health-related online support groups by accessing the perspectives of parents who are caregivers to an adolescent with type 1 diabetes. This offers an important and hitherto unexplored insight into the role online support groups can have for parents affected by what has been called a 'family disease' (La Greca 1998).

Participants completing the online survey for Study 1 reported experiencing a range of empowering processes as members of diabetes online support groups. These included 'finding a safe place', 'exchanging information', 'finding recognition', 'sharing experiences', 'helping others', and 'encountering emotional support'. Furthermore, they reported being empowered as a consequence of 'being better informed', 'enhanced social well-being', 'feeling more confident about the treatment', 'feeling more confident in the relationship with their child's healthcare team', 'improved acceptance of the illness', 'enhanced self-esteem', and 'increased optimism and control over the future'. These results are supported by the findings from the qualitative interviews carried out for Study 2, and further corroborated by findings from the third empirical study discussed in Chapter 7.

8.3.1 The empowering processes occurring within diabetes online support groups

Research by Merkel and Wright (2012) found parents considered a diabetes online support group to be a ‘safe’ environment in which to share their personal experiences of caring for a child with type 1 diabetes. This observation has been reported across other studies investigating health-related online groups (Barak, Boniel-Nissim and Suler 2008, Coulson and Greenwood 2012, Fullwood et al 2019, Kirk and Milnes 2016, Merkel and Wright 2012, Smedley and Coulson 2017) and was similarly evident in the current research. Parents were more inclined to want to discuss issues surrounding diabetes with other online group members rather than friends or family offline. Being able to access an environment that was perceived to be safe and non-judgemental was particularly pertinent for parents who participated in the Study 2 interviews. Having experienced emotional distress following their child's diagnosis, a sustained sense of guilt was commented upon. Feelings of being judged by other people offline were ameliorated by the belief that the diabetes online support groups provided an online community populated by others with shared interests, perspectives and experiences. As previously discussed, this 'value homophily' can be instrumental in establishing trust in online support groups (Centola and van de Rijt 2015, Sillence 2017, Wang et al 2008). As a result, members feel the online group to be safe place to disclose and discuss sensitive or emotional topics.

One such emotive subject evidenced in all three empirical studies was the death of a child from diabetes. Often considered a taboo subject, parallels can be drawn with contemporary research on grief and bereavement that has investigated the implications of online support groups for bereaved parents (Cacciatore et al 2013, Finlay and Krueger 2011, van der Houwen at al 2010). Christensen et al (2017) noted that parents in online grief support groups formed social enclaves where they could negotiate meaning in a safe online environment. Somewhat controversially, the authors argue that rather than this contributing to de-tabooing the loss of a child, such online groups might potentially reinforce present taboos as they endorse the segregation of grief practices from the wider offline society. Within the current study there was no evidence to support this view. Conversely, having the opportunity to discuss such sensitive topics or observe other members online conversations was not only informative for parents, but also as reported in Study 1 and 2, gave them the confidence to broach these issues with other people offline. This included other family members, health professionals and crucially, their child with diabetes.

This has been viewed as particularly important for parents relinquishing control of their child's diabetes management, whilst also attempting to adjust to the evolving shift in their respective roles (Holtslander et al 2012, Ness, Saylor and Selekman 2018). Findings from the Parents Diabetes Distress Scale as part of the online survey discussed in Chapter 5, showed parents had concerns about their adolescent’s ability to achieve optimal diabetes control by themselves, without parental intervention. These concerns, along with a very real fear about death were raised again during the interviews carried out for the second study. Participants vocalised their gratitude for the online environment where they could safely *'be emotional*' or *'just vent'* without fear of reprisal or rebuttal. Unlike face-to-face interactions, where conveying emotions about sensitive or taboo subjects could be frowned upon due to social norms or conventions, online groups gave parents the opportunity to express their emotions more freely. It should be noted that all interviewees were mothers, and it has been reported that fathers may not convey their emotions as freely or as easily as mothers appear to do (Bowes et al 2009, Ware and Raval 2007). Nevertheless, messages analysed for Study 3 identified emotional expressions posted by fathers. These not only related to their child’s diabetes, but also to more personal relationship problems. This is an important finding. It adds to the limited body of knowledge about how fathers of children with diabetes use online support groups, and provides further evidence around the emotional benefits of such online communities for an under-researched cohort.

The findings of the empirical studies carried out for this thesis suggests one of the initial reasons for parents of children and adolescents with diabetes to join a diabetes online support group was for recognition. In line with previous research, locating other parents facing similar issues and challenges related to type 1 diabetes helped group members feel less socially isolated and more aware that their situation and emotional responses were not unique (Balkhi et al 2014, Merkel and Wright 2012). In keeping with the homophily principle applied to social networks, similarity builds connections (McPherson, Smith-Lovin and Cook 2001). Not only is this valuable following a diagnosis of diabetes that led parents to join an online support group, but it also continues to be so as member's children develop and deal with issues related to the different phases of the disease trajectory. Likewise, lateral comparisons could be made between empathetic members with similar or shared experiences across these different stages. This provided a sense of validation that helped address and assuage negative diabetes experiences some participants in the current study had previously experienced offline. It was also noted that being able to view and consider these comparisons across an extended time period provided hope and gave participants in the current study more confidence overall about the future.

A notable finding of this thesis was the importance parents within the diabetes online support groups placed on exchanging information and experiential knowledge about type 1 diabetes. Consistent with past research (Gilbert et al 2012, Nicholas et al 2013, Nordfeldt et al 2013) this was predominantly focussed on information about diabetes management relating to clinical aspects of the disease. This included technical information about insulin delivery, type and dosage, plus practical information for managing complications such as hypoglycaemic episodes at night. Parents were able to arm themselves with the necessary information required to support their child’s physical well-being from the online support groups. However, it was consistently apparent across the three studies that information from diabetes online support groups was offered to complement and supplement that which came from health professionals, rather than an attempt to reject or usurp the medical profession (Henwood et al 2003, Oser et al 2017). Indeed, there was a reported degree of organised moderation by all the online support groups included for consideration in the current research. This was employed to curtail the spread of misinformation regarding diabetes, with parents advised to only make medical decisions based on advice from their own health care team. Striving to protect the integrity of the information within the online support groups further reinforced the perception of these communities being safe and trustworthy environments as previously discussed.

As parents of adolescents, the opportunity to be included in discussions with the NHS healthcare team will be reduced significantly as their child transitions into adult diabetes services (Allen et al 2011, Winocour 2014). With this clinical resource restricted or no longer available, the diabetes online support groups continue to serve as a convenient and readily available repository for accessing information. This was found to be the case for parents in the current research that reported using the groups for informational support during the early hours of the morning; further evidence of optimal matching in the types of support offered. Similarities can be drawn here with research from Nordfeldt et al (2013) who found parents of adolescents with diabetes sought information online dependent on their life situation, child’s development phase and the disease trajectory.

A key feature within the current research was the reciprocity of sharing personal experiences by members in diabetes online support groups. Parents of children and adolescents with type 1 diabetes valued being able share their personal experiences of living with the disease. It was considered an altruistic act that could benefit or provide support to other parents as demonstrated by participants interviewed for Study 2. Describing their experiences of being new members of their chosen diabetes online group, they appreciated how other group members would willingly share their experiences and found this both informative and supportive. In an effort to '*pay something back*', and as more established group members, they reported they would respond to requests for help or information. Sharing their own experiences with other parents gave them a sense of being a valuable and useful member of the online community (Hadert and Rodham 2008). This supports findings by Brady, Segar and Sanders (2017) who suggest that sharing experiences online affords group members the opportunity to engage in mutually supportive relationships. Here individuals are able to help others by discussing subjects or experiences they felt unable to share with other people offline. Correspondingly, in Chapter 6, parents described the diabetes diagnosis as a traumatic event with emotional consequences and repercussions. Being able to share their stories online not only had the potential to help other group members, but also as Mo and Coulson (2014) suggest, may be therapeutic as it could help them make sense what had happened in the past and to let go of it.

Previous studies have addressed the benefits of online support groups with regard to the emotional support offered to group members (Cacioppo et al 2016, Coulson and Greenwood 2012, Martin et al 2018, Smedley et al 2015, van Uden-Kraan 2009, Sullivan 2008). Commensurate with findings from this body of work, the current research found that emotional support was prevalent and readily available to parents using diabetes online support groups. What this research adds is an interesting perspective on how parents' requirements for this type of support appear to change over time.

Findings from Study 3 showed that introductory posts from parents joining the diabetes online support groups included details of their child's previous ill health and diagnosis. Responses from other members welcoming them to the group contained messages of emotional support, either textual or graphical, such as an emoji. This was also identified as a common occurrence by parents interviewed in Study 2. They explained it immediately gave them a sense of being part of a supportive community at a time many felt support from friends and family was insufficient to meet their emotional needs. Furthermore, this was recognised as an aspect of the online support groups that encouraged parents to continue to use them years after their child's diabetes diagnosis. This is important, as membership retention in online groups, as with those offline, is fundamental in order to sustain them and for them to continue to be effective. In their research with an online cancer support group, Wang, Kraut and Levine (2012) examined the association between the length of membership and different types of support. They found emotional support to be positively associated with how long members remained in the group, and speculated this was as a consequence of emotional support enhancing members relationships with other members and the group overall. Similar findings were evident from Study 1 when considering parental satisfaction with their chosen diabetes online support groups and length of membership. However, previous research has found relationships with online support groups can change over the course of time (Malik and Coulson 2008, Bartlett and Coulson 2011, Alsem et al 2017). It is therefore pragmatic to acknowledge that parents' relationships and requirements from diabetes online support groups change or evolve as they relinquish control of their child's diabetes management, but that emotional support appears to be an important constant that encourages them to remain a part of the online group.

8.3.2 Disempowering processes

The findings from the three empirical studies carried out for this thesis suggest that parents' experiences of diabetes online support groups were viewed as positive, with empowering process and outcomes identified. Nevertheless, a number of potential disadvantages were recognised by participants. Firstly, concerns were raised in Study 1 about the possibility of misinformation or conflicting information regarding diabetes treatment. This could confuse new members or parents of newly diagnosed children were looking for advice, with potentially disastrous consequences. Likewise, in Study 2, participants interviewed raised similar concerns but drew attention to the role of moderators in the groups as a means of preventing the spread of accidental or deliberate misinformation. Oser et al (2017) carried out a qualitative study with two medical doctors assessing the types and quality of information from 140 unique blog posts by caregivers of children with type 1 diabetes. They concluded that clinical or medical misinformation was exceedingly rare in this sample, and in instances where it was discernible, was benign. A significant degree of self-moderation was noted by the study authors, suggesting a transparent accountability in order to prevent diabetes misinformation. Furthermore, as was found in the current research, this helps endorse the information shared as more trustworthy by those viewing it.

Parents using diabetes online support groups reported feeling anxious and upset when confronted with distressing or negative stories about diabetes, such as hospitalisations or the death of another member's child. Comparable with findings from previous studies, reading messages describing experiences with deleterious outcomes could lead to a negative downward social comparison (Locock and Brown 2010, McKechnie, Barker and Stott 2014, van Uden-Kraan et al 2008), with parents fearing the same could happen to their child. Avoiding messages that contained with this type of content was a way for some members to mitigate this. However, in extreme cases where negative feelings became so overwhelming as to become potentially harmful, participants reported temporarily leaving the group as a coping strategy.

8.3.3 Empowering outcomes

The findings presented in this thesis strongly suggest participating in diabetes online support groups can help empower parents of adolescents with type 1 diabetes. The results from the 3 empirical studies demonstrate how online empowering processes can facilitate empowering outcomes outside the online community that include being better informed, enhanced social well-being, feeling more confident about treatment and improved acceptance of the disease.

Quantitative results from Study 1 shown in Chapter 5 found the empowering outcomes experienced to the strongest degree were 'being better informed' and 'enhanced social well-being'. Similar findings have been shown in past research for specific health conditions such as breast cancer, fibromyalgia, arthritis, HIV, and eating disorders (van Uden-Kraan et al 2008, Mo and Coulson 2013, Aardoom et al 2014). Whilst the empowering benefits for parents as caregivers participating in online support communities has not been as comprehensively explored, this congruency with the extant literature adds gravitas to the hypothesis that participating in diabetes online health communities benefits not only those individuals who are patients but also those who are caregivers affected by this 'family disease' (La Greca 1998).

A notable finding from this thesis was that all participants reported being better informed as a consequence of joining a diabetes online support group. Overwhelmingly, it was reported in Studies 1 and 2 the initial requirement of parents from the online group was a need to obtain as much information as possible about the disease and disease management following their child’s diagnosis. Whilst given clinical instructions by health professionals, the complexity of disease management required a depth of clinical knowledge and understanding many did not possess. The unpredictable nature of diabetes also meant there was often an urgency or expediency for information relating to treatment to avoid diabetic complications. As previous research indicates, engaging with the online groups gave parents the opportunity to improve their knowledge about the disease modality through observations or interactions with others who could offer experiential knowledge and advice (Buchanan and Coulson 2007, Brady, Segar and Sanders 2017, van Berkel, Lambooij and Hegger 2015). It was empowering for parents to have access to a convenient informal database of diabetes knowledge, experience and advice available in message threads. This meant that at times, rather than posting a new message or asking a question and waiting for a response, parents could carry out a historical search of messages in the online groups for information as needed (Drentea and Moren-Cross 2005). Parents in Study 2 reported they used the informational support offered by the diabetes online support groups in tandem with that from health professionals when their child was first diagnosed. As with the construction of 'patient knowledge' (Pols 2014) parents using the diabetes online support groups were able to amalgamate the personally trusted online experiential knowledge and the NHS sanctioned offline clinical knowledge to create a 'third form' of knowledge that was practical and addressed their changing needs. Importantly when direct contact with the healthcare team was reduced as adolescents became responsible for their own diabetes management parents still felt confident about the experiential knowledge and information they were able to obtain from the online groups. They believed it to be an on-going support community and information repository they could access for their specific needs at their convenience, unlike that from their child's healthcare team (Keeling, Khan and Newholm 2013).

As a result of becoming better informed about diabetes by obtaining information and nuanced advice from the online support groups, including information that could not be found elsewhere (Barker 2008), parents reported feeling more confident in the relationship they had with their child's healthcare team. Laing, Keeling and Newholm (2011) suggested individuals participating in online support groups can develop a greater sense of ownership over their illness or condition, which can lead to them becoming more engaged with the health professionals they interact with. This idea is also applicable to parents still co-managing their child's chronic condition. Participants in the current study described how the diabetes online support groups could be used as a sounding board for members to '*bounce around*' ideas before they consulted with healthcare professionals. Members would often feed back to the group their experiences of clinic appointments and share any new information they thought would be of interest. Again, this highlights the reciprocity of information exchange with the online support groups.

A novel finding from Study 2 was the importance parents of adolescents in the diabetes online support groups placed on having continued confidence in their child's healthcare team when they had relinquished responsibility for diabetes management. Transition to adult diabetes services has been shown to be stressful for both the adolescent and parent (Markowitz, Parsons and Advani 2017). In a longitudinal qualitative study, Allen et al (2011) identified that for mothers, loss of contact with the healthcare team could lead to a discontinuity of information, undermining their ability to support their child as they took over their own diabetes management. However, the diabetes online support groups provided not only experiential information, but also that which came from authenticated respected agencies via links to external websites. This helped parents keep up to date with clinical innovations, research and in certain instances legislation appertaining to diabetes. These varied sources of information appeared to give participants in the current study more confidence about present treatment regimes for diabetes as well as increased optimism and hope for the future. Much of this stems from the opportunity for social comparison within the online support groups (van Uden-Kraan 2008, Setoyama et al 2011). Although as pointed out by Batenburg and Das (2015), there is a risk that members of online support groups can become entrapped by negative social comparison processes, affecting psychological well-being.

No longer advocates for their adolescent's diabetes healthcare, parents in Study 2 reported their relationship within the online support groups had evolved during their membership from being supported to that of supporting other group members. This has similarities to findings from Kerr and McIntosh's (2000) research exploring the impact of parent-to-parent support for parents of children born with a disability. After months or years of being the recipient of informational, emotional and social support from parents in the same situation, they reached a point where they felt able to offer advice and support to others. The authors described this as 'coming full circle' and noted the empowering benefits for both the provider and recipient of the support. In the current research, this evolution of roles within the diabetes online support groups and the decision of members to remain in the group appeared based on their evaluation of how beneficial the online group had been in the past and the likelihood of this continuing in the future (Levine and Moreland 1994, Yang, Kraut and Levine 2017).

The level to which enhanced social well-being was reported as an empowering outcome in Chapter 5 was a strong indicator that the online support groups provided a useful environment where social networks could be established (van Uden-Kraan 2008). For parents affected by the events of their child’s diabetes diagnosis, connecting in the first instance with empathetic others in a similar situation to their own helped them feel less isolated and lonely. Similarly, for parents dealing with nocturnal hypoglycaemic episodes, identified in a number of message posts analysed for Study 3, the experiential advice plus emotional support they received from other members online reassured them they were not alone. It has been shown that members who were willing and able to offer advice and support benefit from an increased sense of self-esteem (van Uden-Kraan et al 2008). Such responses identified in the current research provided a sense of solidarity and further served to reinforce the integrity of members, helping establishing trust in the online support group. This point has been echoed by previous research which suggests people have a tendency to believe that information contributed by similar others is more credible, and are therefore more likely to act on this information (Flanagin, Hocevar and Samahito 2014). As identified in Study 2, this type of engagement with other members from the online support group helped create a familiarity that in certain instances then developed into an offline friendship between parents. Wright (2016) theorises that previously 'weak tie' relationships (Walther and Boyd 2002) in the online community may evolve into stronger ties offline, but as the author acknowledges, this warrants further investigation to measure and address how the strength of ties between the online support group members changes over time.

8.4 Diabetes Distress

The psychological impact of parenting a child with type 1 diabetes should be not underestimated. Whilst current clinical guidelines recommend diabetes management is initially overseen by parents after diagnosis (NHS 2016), for many this can be a daunting and emotional prospect. Parents are expected to quickly acquire a working knowledge and understanding of the disease, whilst assuming responsibility for complex clinical and lifestyle regimes necessary for optimal glycaemic control to avoid life threatening consequences (Wennick and Hallstrom 2006). These newfound responsibilities have been described as '*all consuming*' by parents (Whittemore et al 2012), with the deleterious impact of diabetes extending beyond the immediate health concerns for their child and into the future.

As research previously discussed in this thesis has highlighted, for parents of adolescents, managing and coping with their child's condition can contribute to negative psychosocial outcomes manifesting as psychological disorders such as anxiety, stress, depression or diabetes distress (Haugstvedt et al 2010, Hessler et al 2016, Law et al 2013, Rankin et al 2016, Rumburg et al 2015, Streisand et al 2008, Williams, Laffel and Hood 2009). Corroborating results from the online survey carried out in Study 1 identified over a third of respondents had been diagnosed or treated for a mental health problem, including depression and anxiety (n=32, 36%) in the last 12 months. Furthermore, evidence of diabetes distress was ascertained from the results of the Parents Diabetes Distress Scale (PDDS).

Whilst the overall score from the PDDS showed moderate levels of diabetes distress, respondents reported a high level of 'teen management distress' indicating they believed their child would struggle to maintain optimal glycaemic control without parental co-management. Concerns about their own quality of life being affected by diabetes was also shown to cause moderate distress, and both significantly correlated with the parent/teen relationship distress subscale that addressed conflict and disagreements with their child. These points were also raised during the qualitative interviews for Study 2 when participants spoke about the future and anxiety they had about their child becoming responsible for their own diabetes management. The fear of diabetic complications due to treatment mismanagement or death was not viewed as being an over-anxious parent but was seen as a rational fear and a continual stressor. Similarly, in a small qualitative study, Ness et al (2018) found mothers of adolescents with type 1 diabetes who were moving to college had similar concerns and fears about their child's ability to manage their condition. Parents in a related study carried out by Ersig (2019) described diabetes as an '*all day everyday concern*' that continued to cause stress even when their child was no longer living at home.

For parents in the current research exhibiting high levels of diabetes distress, the diabetes online support groups appeared to provide a number of beneficial key functions. As previously discussed in this thesis and in line with findings from with past research, they provided a safe environment where parents could share their experiences, exchange information, and receive emotional support (Coulson and Greenwood 2012, Merkel and Wright 2012, Sullivan 2008, Teasdale, Muller and Santer 2017). Findings from Study 2 revealed it to be an amalgam of these aspects of the online communities that parents exploited to their advantage in order to cope with the emotional stressors diabetes imposed.

A further interesting finding that came from the qualitative interviews was the pragmatic approach some parents adopted when encountering negative aspects of living with diabetes or traumatic events such as the death of a child on the online support groups. It could be supposed this would have a detrimental effect on levels of diabetes distress, or in certain circumstances people might leave the online group (Sandaunet 2008). However, in the current research it appears that social comparison strategies are used by individuals, and dependent on the type, these can determine the psychological effects of participating in an online diabetes support group (Buunk et al 1990).

It was not within the scope of the current research to ascertain if participating in diabetes online support groups could reduce the levels of diabetes distress for parents due to the research methods employed. Despite this, the findings from the three empirical studies would indicate that the unique characteristics of diabetes online communities and the benefits group membership affords parents of adolescents with type 1 diabetes shows promise for actively managing *'the negative emotional or affective experience resulting from the challenge of living with the demands of diabetes'* (Polonsky et al 1995).

8.5 Methodological issues

The growth of the Internet has provided researchers within the social sciences new and novel opportunities to engage participants in research. Adopting the perspective of the Internet as a research tool, it has the potential to effectively address and overcome a number of critical research challenges such as recruiting, retaining and tracing participants (Thornton et al 2016, Nwadiuko et al 2011**,** Mychasiuk and Benzies 2012). Whilst the strengths and possible limitations of various online research methods and associated ethical implications were previously discussed in Chapter 4, it is apposite to reference these in the context of the current research; acknowledging any methodological issues or challenges that arose during the research process and how these were addressed.

Whilst more traditional approaches to engaging parents of children with diabetes in research have been utilised (e.g. postal questionnaires, focus groups, face-to-face interviews) these have been considered increasingly ineffective in recruiting and retaining research participants. A possible explanation for this is a reluctance of researchers to acknowledge the change in the technological landscape and shift towards digital communication practices that have become more ubiquitous (Harris et al 2015). As the focus of the current research was an investigation of parents’ use of diabetes online support groups, choosing to recruit participants online was eminently pragmatic and appropriate. However, recruitment from the online diabetes support groups previously identified as meeting the criteria determined for Study 1 proved to be challenging.

In the first instance, an administrator for each of the twenty-five eligible groups was contacted via email. This email introduced the researcher, gave details of the study and requested permission to post the online survey on the group site. Disappointingly, a third of the moderators contacted refused to post details of the online survey, with a number citing concern about member’s privacy being compromised. This response did not appear to be the consensus of the group members, but rather, a decision taken by individual moderators acting as community 'gatekeepers'. This type of negative response towards requests from researchers wishing to engage with members of online support groups whilst not uncommon (Roberts 2015) is frustrating. It may not only delay research, but denies group members the opportunity to engage in research due to moderators adopting an over-protective paternalistic attitude (Goldsmith and Skirton 2015). This 'over-protection' as it relates to the current research may be interpreted as an attempt by the moderators to ensure the continued privacy and confidentiality of group members due to the sensitive and personal nature of the information and communication in the diabetes online groups. Barzilai-Nahon (2006) has examined gatekeeping practices in online groups, and has emphasised the dual role of moderators as not only censor but also protector. However, this aspect of Internet based research and online recruitment is intrinsically imbued with ethical and legal considerations researchers must appreciate (Curtis 2014, Henderson et al 2013, Moreno et al 2013).

The previous paucity of ethical guidelines related to Internet health research has been addressed more recently, with researchers and strategists emphasising not only the importance of such guidelines being implemented and adhered to, but also noting the need to be updated to reflect and keep pace with continued technological advances (Bender et al 2017, Crawford et al 2019). The British Psychological Society guidelines for Internet-mediated research (BPS 2017) were consulted during the design and planning stages of the current research. In line with the principles espoused, every effort was taken to ensure the anonymity, privacy and dignity of all participants was upheld. This point was reiterated in a follow up email to the moderators who had declined to take part in the research asking them to reconsider their decision. Only one moderator responded to the follow up email, providing an explanation for why they would not post details of the online survey. Researchers from a private drug company had previously been granted access to the group, but it was felt the research conducted was intrusive and disruptive. Group members complained about receiving repeated unsolicited private messages asking for additional information and sending links to other research projects and websites.

This reported negative experience raises a further ethical consideration when requesting to conduct research in online support groups, that of 'survey fatigue' (Roberts and Allen 2015). Group members can be overwhelmed by frequent requests to take part in online surveys, and the demand to participate increases the respondent burden, which can conversely result in reduced response rates (Porter, Whitcomb and Weitzer 2004). Whilst assurances were made to the moderators confirming only one survey from this researcher would be promoted on the group, and member’s privacy would be respected, permission was still not granted. However, there is a case to be made for recognising that whilst the moderators refused to post details of the online survey for Study 1, believing this to be in the best interest of the online community, they may be denying members potentially benefiting from engaging in research. This poses the question, should all group members be eligible to have a say in whether details of research studies and invitations to participate are made available to the group? The logistics of how such a referendum could be managed are complicated and not within the scope of this thesis, but this is an interesting issue about online community dynamics that potentially warrants further investigation.

Another important ethical issue to consider when conducting research with online communities is that of mitigating the risks for researchers. It is an overlooked aspect of Internet mediated research, yet congruent with the safety concerns identified for participants engaging in online research (Sharkey et al 2011). It has been acknowledged that whilst researchers undertaking fieldwork may be at risk of physical danger, the perceived risk when interacting with participants electronically appears significantly less so (Johnson, Lawson and Ames 2018). What may be compromised is the researchers privacy, resulting in unwarranted or negative consequences such as online harassment or abuse. If not addressed and curtailed, this may accelerate and in extreme circumstances pose physical danger to the researcher (Marwick, Blackwell and Lo 2016).

During the current research when the link to the online survey for Study 1 was posted on the participating diabetes online support groups, one group member (who identified as male) started to post increasingly disparaging remarks about the research project. Over a period of days, the posts from this member escalated from reproachful critiquing of the online survey, which he had accessed but not completed, into personal criticism about this researcher. The researchers academic and professional integrity were publicly called into question, along with that of the University of Nottingham. The effect of this online 'trolling' was not only potentiality detrimental to the recruitment of participants, but was also emotionally stressful for this researcher. A group moderator was contacted to report this targeted harassment, and the member in question was formally warned they were in breach of the group's publicised ethos and rules. More disparaging posts were made before the moderators decided to delete all the posts and permanently ban this member from the group.

What this episode highlighted is that there is a real threat of online harassment, abuse and aggression being directed towards researchers attempting to engage with online communities. Moderators in their role as gatekeepers may sanction research within the online community but not all group members may be receptive to this. Some may consider it an invasion of privacy, whilst others query the motives of those carrying out the research (Golder et al 2017). In a recent review of the latest BPS guidelines for Internet mediated research Caldwell Brown (2018) drew attention to the issue of misinformation and conspiratorial thinking by web-users who objected to having their online discussions analysed by researchers and disseminated in academic literature. Taking these considerations into account, universities and those agencies sanctioning and conducting Internet mediated research need to prepare and support their researchers to deal with these potential issues and challenges should they arise.

Whilst impossible to determine with any certainty if recruiting from a lower than anticipated number of online diabetes support groups affected the overall response rate for the Study 1 online survey, steps were taken to ensure details of the research and 'invitation to participate' post remained visible to members. Moderators were asked to pin the post to the homepage where appropriate, and it was agreed across all the sites hosting the survey link that 'progress' updates would be posted during the recruitment period. This was intended to give group members a sense of being part of a collaborative research process, and was extremely well received. Group members posted positive comments about the research, with a number asking if it was acceptable to share the link with other people they thought would be interested in taking part. In this circumstance, they were thanked and encouraged to share the study details.

Feedback about the design of the questionnaire was also given by group members, with the majority of responses being overwhelmingly positive. Constructive criticism came from a very small number of members, namely addressing the length of the online survey, and the time taken to complete it. This is a consideration researchers designing surveys and questionnaires should take into account (Galesic and Bosnejak 2009). Nevertheless, there can be a discrepancy between the times respondents take to complete surveys. This may be dependent on their thought process before answering questions and the amount of information they provide if a survey asks them to write their own thoughts or opinions. The qualitative data obtained from the open-ended questions included as part of the Study 1 online survey varied between respondents. A number provided brief answers, but the majority of participants provided more extensive and detailed information about their experiences of using diabetes online support groups. Whilst arguably more time consuming for participants, the ability to consider and reflect on their answers provided rich data for analysis. This can be considered a significant benefit of using this methodology.

Whilst the design of the online survey for Study 1 might be considered ambitious, the sample size was comparable or greater than past research examining the online experiences of parents of children with chronic health conditions (Balkhi et at 2014, Clifford and Minnes 2013, Sage et al 2018). Nevertheless, choosing to recruit participants directly from diabetes online support groups by posting details of the study with a link to the online survey, whilst a pragmatic decision, is also one that presents with the potential for self-selection bias (Bethlehem 2010). It would be disingenuous to imply that the resultant sample was representative of all parents with a child with type 1 diabetes; it is merely representative of those parents who accessed the diabetes online support groups and completed the online survey. There may be a disparity between group members, with established or active contributors more likely to respond to an invitation to participate in research, in contrast to new or infrequent members or those who choose to 'lurk'

(Edelmann 2013, Han et al 2014, Merry and Simon 2012, van Uden-Kraan et al 2009).

Another consideration with the recruitment strategy used in the current research is that it prohibits the application of a sampling frame. This has implications regarding the ability to assess the response rate and draw comparisons between respondents and non-respondents (Hewson 2003). In an attempt to address this, it has been suggested that online surveys may be distributed by email directly to group member, either as a URL link in the body of the email, or as an attachment (Gaiser and Schreiner 2012). Whilst this may be advantageous in terms of obtaining greater information about the population size and characteristics of the online group under consideration, it raises questions about group privacy and data protection issues. Group members have an expectation of privacy online and that extends to personal details such as email addresses being distributed without their permission. Moderators of online support groups may receive requests from researchers for mailing lists of group members email addresses, but it is at their discretion if this information is divulged. Furthermore, the response rates to surveys using direct email contacts are reported to be typically low (Dillman, Smyth and Christian 2014). Other drawbacks noted are that people may change their email address or have multiple accounts they no longer use. Emails will not be delivered if the address is misspelt or spam filters are in place and the email is misconstrued as spam and deleted.

There is evidence that demonstrates the wording and images used in research recruitment posts online can affect the respondent rate (Ramo and Prochaska 2012). In a study comparing research advertisements on Facebook, the authors found those with the study logo received more clicks (Ramo et al 2014). In an attempt to maximise the response rate from potential participants a similar technique was used for the current research. The University of Nottingham logo was included in the introductory post hosted on each of diabetes support groups with the link to the online survey. This logo was again evident on the landing page of the survey and on each page thereafter. At the start of the interviews carried out for Study 2, as part of the 'icebreaker' questions, participants were asked their general thoughts and opinions about the online survey they had previously completed. The university logo was commented on, with more than one participant reporting they had Googled 'University of Nottingham' comparing the image from the survey with that on the university website to check the provenance of the researcher and the research request. This gives credence to the notion that parents accessing online health communities are not only becoming increasingly Internet and eHealth literate, but are having to become more 'Internet savvy' due to the proliferation of potential scammers and an increase in sophisticated cybercrime (Saunders 2017). Particularly pertinent to diabetes online support groups are those individuals or organisations that are able to infiltrate the group to post offers or links to 'miracle cures'. These scam posts will often involve social proof cues such as fake recommendations or celebrity endorsements (Lea, Fischer and Evans 2009). At best the products or information being touted is harmless, at worst, potentially life threatening (DiFonzo et al 2012).

An issue that can affect an increase in the response rate yet conversely skew the data when employing online surveys is that of multiple responders. The integrity of the data will be compromised if participants have multiple online identities and complete the survey multiple times (Quach et al 2013). This issue may be further complicated if financial incentives are offered for participation, which may encourage respondents to participate for financial gain (Arigo et al 2018). This was not the case in the current research. The Bristol Online Survey (BOS) software used to host the online survey for the present research had the capability to block more than one response from any single IP address but this was not activated. This decision was taken to guard against the possibility of precluding people who share the same IP address from completing the survey. A manual review of the IP addresses from all respondents, and any email addresses submitted within the online survey was carried out. No evidence of duplication was found, but this is a consideration researchers should take into account when conducting online research.

Despite a number of challenges encountered during the current research, the use of a triangulated methodological approach proved to be effective in meeting the original aims of the thesis. Of significant benefit were the rich qualitative data accumulated from the three empirical studies. Most notably, the naturally occurring data obtained from the messages posted on diabetes online support groups and analysed in Study 3. Uninfluenced by the presence of a researcher, these online dialogues between group members provided an in-depth unexpurgated account of the lived experiences of parents co-managing their child's chronic health condition. They served to highlight not only the requirements but also the expectations members had from a diabetes online support group, whilst demonstrating the ways in which these were met. Presenting a 'snapshot' of the activity and communication that took place during a designated period time, this rich data supports and supplements the findings of the two previous studies. It further substantiates the reported psychological impact of diabetes distress experienced by parents in Study 1 and makes evident the different types of social support identified in the current research.

8.6 Directions for future research

The findings from the empirical studies carried out for this thesis provided important and original insights into diabetes online support groups for parents of children and adolescents with type 1 diabetes. This not only adds to the current limited body of knowledge regarding a cohort not widely studied in an online environment, but also after reviewing the results presented in Chapters 5, 6 and 7 raises some interesting issues with implications for future research. These will now be considered.

8.6.1 Addressing the gender disparity

As mentioned previously in this chapter a significant disparity was noted between the genders of participants. 99% of respondents who completed the online survey for Study 1 identified themselves as female and a mother, with 1 male respondent. Nevertheless, analysis of the data obtained for Study 3 (see Chapter 7) provided evidence that a small number of fathers were actively participating in online diabetes support groups: asking for advice about diabetes management, sharing details of their experiences of dealing with their child's diabetes, and offering to communicate with other members offline. The nature of these online dialogues was consistent with those taking place between mothers, suggesting that fathers may also experience diabetes distress and were looking for social support online.

Whilst the research investigating fathers' experiences of parenting a child with diabetes is comparatively sparse against that considering mothers' experiences (Nieuwesteeg et al 2017), there are a limited number of studies which have explored paternal stress and coping behaviours related to diabetes (Limbers and Teasdale 2018, Mitchell et al 2009, Seiffge-Krenke 2002, Sullivan-Bolyai et al 2006). Not only can this type of stress have a detrimental effect on father's psychological well-being, but it also has important implications for metabolic control and health outcomes in children and adolescents (Hilliard et al 2011, Maas-van Schaaijk et al 2013) and maternal mental health (Hansen et al 2012). This reinforces the line of reasoning that diabetes is a 'family disease' (Williams, Laffel and Hood 2009), a concept that has been examined within the paradigm of family systems theory (Helgeson et al 2012, Perry 2015, Wiebe, Helgeson and Berg 2016). To that end, it seems appropriate to speculate that as mothers of children with type 1 diabetes have found using diabetes online support communities empowering and reported positive psychological outcomes with regards to the different types of social support they have encountered, so fathers could likewise benefit from engaging with 'similar others' online. Corroborating evidence to support this can be found in previous research where use of online support groups has been shown to have a positive psychological influence for men across a variety of male-centric health conditions such as prostate cancer, testicular cancer and male infertility (Bender et al 2012, Broom 2005, Hanna and Gough 2016). However, the extant literature examining the role of paternal online support communities for fathers of children with chronic health issues is scant at best (Nicholas et al 2004, Nicholas et al 2012). Father's perspectives about their online experiences relating to diabetes are more often included under the auspices of research that addresses 'family' or 'parents' perspectives (Balkhi et al 2014, Merkel and Wright 2012, Niela-Vilе́ et al 2014). Such homogeneity does not allow for differentiations between the social support needs of mothers and fathers, their motivations for using online support groups and the consequences thereof to be identified. This raises questions about how to best engage fathers in online research.

The use of targeted, highly specific, paid for advertisements on social media platforms such as Twitter, Facebook and more recently Instagram, has become an increasingly adopted means of promoting research to hidden or hard to reach communities in virtual environments (Close et al 2013, Choi et al 2017, Guillory et al 2018). Whilst social media is free, advertising in this medium can be costly and budgetary constraints need to be taken into account when planning the study design. Although not a feasible option for the current research, this could be a viable and digitally appropriate method to optimize reach and participant recruitment of fathers of children with type 1 diabetes.

Another approach that could be used to specifically target fathers would be to develop and host a bespoke online forum (Armstrong, Koteyko and Powell 2012, Smedley et al 2015). This method requires particular IT skills and resources in order to be implemented. It can be labour intensive, time consuming and incur associated financial costs. Yet if well designed and managed ethically, has the potential over time to develop into a selfsustaining online community. As part of a longitudinal study, an approach not evident in the research literature with this cohort, such a strategy could provide benefits for forum members and also give researchers a greater insight into how and why fathers per se chose to use diabetes online support groups.

8.6.2 Engaging with health professionals

Parents of adolescents with type 1 diabetes are shown to engage with diabetes online support groups for informational and emotional support. Reported as complementing and often supplementary to the information received from healthcare professionals, as the findings from the empirical studies in this thesis suggest, it is trusted, albeit with caveats noted. This is important, as misinformation about diabetes treatment or unsubstantiated clinical recommendations may put patients at risk and have significant consequences (Hilliard et al 2015, Oser et al 2017, Weitzman et al 2011). Whilst a body of research has addressed these notions of advice and the antecedents of trust in health-related online support groups (Brady, Segar and Sanders 2016, Lovatt, Bath and Ellis 2017, Sillence 2013, Sillence 2017), less is known regarding how this is considered and interpreted by health professionals involved in diabetes care (Gilbert et al 2012). This raises some interesting questions about the role health professionals believe online support groups have for people affected by diabetes, and if there is an argument to be made for more collaborative online participation between patients, other users such as parents and healthcare professionals (Vennik et al 2014, Waite-Jones and Swallow 2018).

In a qualitative study, Atanasova, Kamin and Petrič (2017) explored the main benefits and challenges faced by healthcare professionals participating as moderators in online health communities. The small study (n=7) identified the healthcare professionals perceived themselves as facilitators of other users empowering processes and outcomes, similar to those reported by participants in this thesis. Whilst the authors considered the online health communities places where health professionals and others engaged in a relationship that could lead to more open, instructive, consultative, and educative approach, they did not explore the experiences or gauge the opinions of non-health professional members. The authors addressed this in a later study where they compared the benefits and challenges of online professional-patient interactions for users and health professional moderators. Both groups considered the primary benefit of the online interaction to be the delivery of informational and emotional support for users (Atanasova, Kamin and Petrič 2018).

With the findings from Atanasova and colleagues' studies in mind, it is interesting to speculate if parents of adolescents with diabetes would appreciate any benefit by interacting with healthcare professionals in diabetes online support groups, as they lose this contact when their child transitions into adult diabetes services. This was a point raised during the qualitative interviews carried out for the second study. Identifying any benefits and investigating if they supplement or suppress those reported from members of diabetes online support groups in this thesis could be useful for health professionals to consider when implementing and managing the transition of adolescent patients. Benefiting not only the patient, but also helpful in managing the expectations or concerns of parents and carers, this type of online collaboration warrants further investigation to consider the views of both those using diabetes online support groups and healthcare professionals. As Marcu, Black and Whitaker (2018) have advocated, healthcare professionals should invest greater efforts to educate their patients about trustworthy online health resources, but perhaps there needs to be a reciprocal exchange of knowledge and requirements from those with first hand experience of using and participating in online support groups.

8.7 Conclusion

The Internet now offers a wealth of health information for a plethora of illnesses and chronic conditions. Online health-related support groups can provide a platform that not only helps individuals obtain information appertaining to their specific health concern, but also affords them the opportunity to seek and provide support. Building on this supposition, the present research sought to explore how and why parents of adolescents with type 1 diabetes chose to use diabetes online support groups, and the consequences thereof. Parents were motivated in the first instance to join a diabetes online support group to connect with others who understood the disease and shared the same experiences and concerns. Findings from the 3 empirical studies show information of a clinical nature obtained from the diabetes online support groups was considered supplementary to that which came from established healthcare professionals. This augments previous research that has emphasised the importance of trust and credibility in online support groups; imperative when clinical misinformation, however well-intentioned could have significant consequences. Moreover, exchanging factual information about diabetes and personal experiences within the online group appeared to contribute to a sense of empowerment for parents. Informational support and emotional support continued to be important requirements for parents whose direct involvement in their child's diabetes management was being rescinded. The online support available was valued by parents who acknowledged the effect this had on their psychological well-being.

In conclusion, this thesis presents a novel insight into the online experiences of parents of adolescents with type 1 diabetes. The findings offer valuable perspectives from a cohort facing a shift in role and parental responsibility, and highlights how the online groups play a unique role in meeting the needs and expectations of these individuals.

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Appendices

Appendix A: Introductory message post and invitation to take part in Study 1 - online survey

Hello everyone, I'm a PhD researcher at the University of Nottingham looking at how and why parents of young adults aged 16-19 with type 1 diabetes use diabetes online support forums.

This research is different from a lot of other studies, which tend to concentrate on the medical side of diabetes management rather than asking people who live with diabetes about their thoughts and feelings.

My interest in this area is a long held one as both my father has, and grandfather had diabetes, so I've seen first hand the effect this can have on the family. The study is an online questionnaire, all participants will remain anonymous, and the results will be confidential. There's also the chance to win a £50 Amazon voucher when you've completed the questionnaire.

If you're interested in taking part, please click on the link below and feel free to share it with anyone you think might be interested -

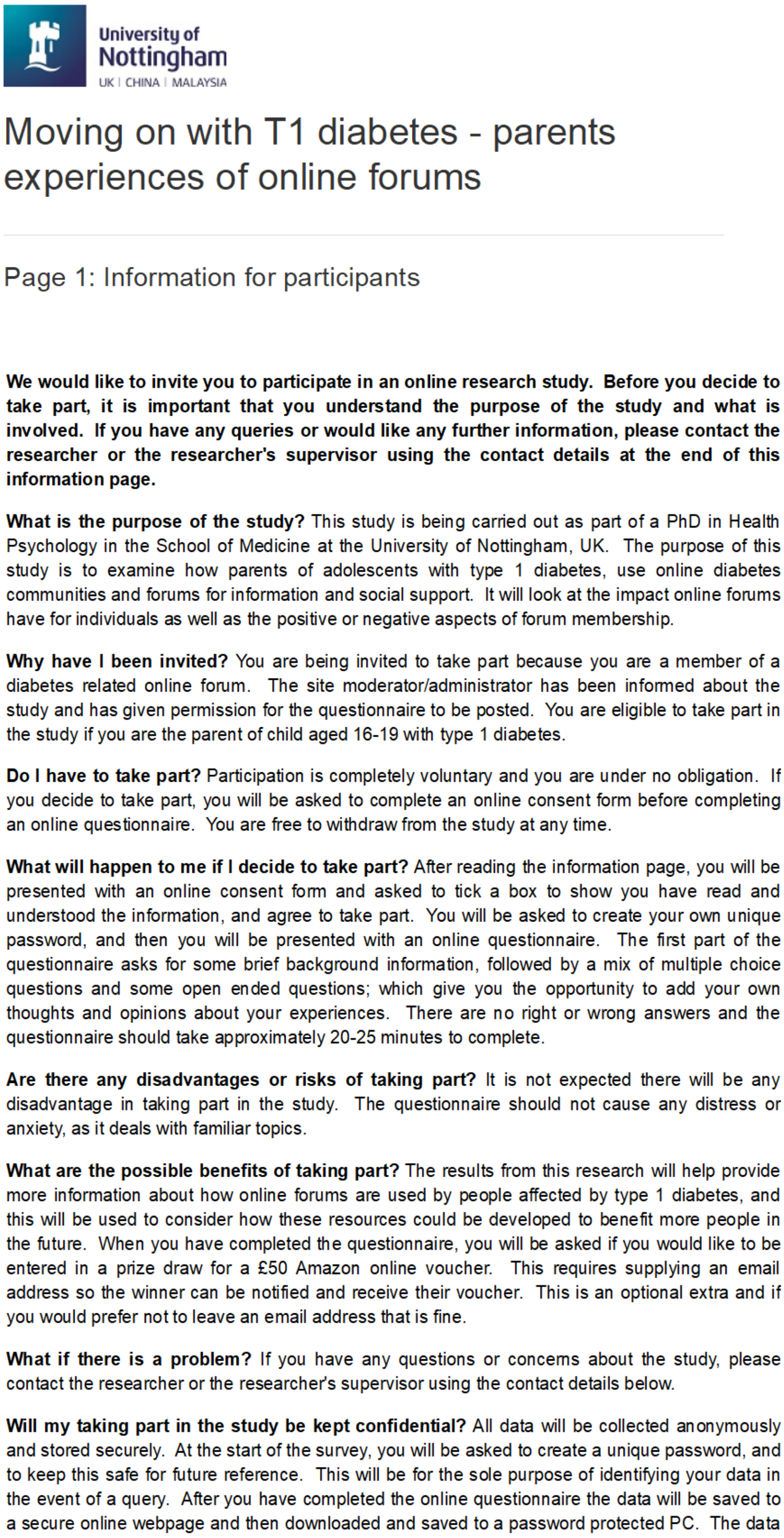
https://nottingham.onlinesurveys.ac.uk/moving-on-with-t1...

Any questions please contact me - msxkls@nottingham.ac.uk

Thanks for reading this, I appreciate people taking the time.

Karen Shepherd

Appendix B: Example of the online survey used for Study 1



University of Nottingham
UK | CHINA | MALAYSIA

Moving on with T1 diabetes - parents experiences of online forums

Page 1: Information for participants

We would like to invite you to participate in an online research study. Before you decide to take part, it is important that you understand the purpose of the study and what is involved. If you have any queries or would like any further information, please contact the researcher or the researcher's supervisor using the contact details at the end of this information page.

What is the purpose of the study? This study is being carried out as part of a PhD in Health Psychology in the School of Medicine at the University of Nottingham, UK. The purpose of this study is to examine how parents of adolescents with type 1 diabetes, use online diabetes communities and forums for information and social support. It will look at the impact online forums have for individuals as well as the positive or negative aspects of forum membership.

Why have I been invited? You are being invited to take part because you are a member of a diabetes related online forum. The site moderator/administrator has been informed about the study and has given permission for the questionnaire to be posted. You are eligible to take part in the study if you are the parent of child aged 16-19 with type 1 diabetes.

Do I have to take part? Participation is completely voluntary and you are under no obligation. If you decide to take part, you will be asked to complete an online consent form before completing an online questionnaire. You are free to withdraw from the study at any time.

What will happen to me if I decide to take part? After reading the information page, you will be presented with an online consent form and asked to tick a box to show you have read and understood the information, and agree to take part. You will be asked to create your own unique password, and then you will be presented with an online questionnaire. The first part of the questionnaire asks for some brief background information, followed by a mix of multiple choice questions and some open ended questions; which give you the opportunity to add your own thoughts and opinions about your experiences. There are no right or wrong answers and the questionnaire should take approximately 20-25 minutes to complete.

Are there any disadvantages or risks of taking part? It is not expected there will be any disadvantage in taking part in the study. The questionnaire should not cause any distress or anxiety, as it deals with familiar topics.

What are the possible benefits of taking part? The results from this research will help provide more information about how online forums are used by people affected by type 1 diabetes, and this will be used to consider how these resources could be developed to benefit more people in the future. When you have completed the questionnaire, you will be asked if you would like to be entered in a prize draw for a £50 Amazon online voucher. This requires supplying an email address so the winner can be notified and receive their voucher. This is an optional extra and if you would prefer not to leave an email address that is fine.

What if there is a problem? If you have any questions or concerns about the study, please contact the researcher or the researcher's supervisor using the contact details below.

Will my taking part in the study be kept confidential? All data will be collected anonymously and stored securely. At the start of the survey, you will be asked to create a unique password, and to keep this safe for future reference. This will be for the sole purpose of identifying your data in the event of a query. After you have completed the online questionnaire the data will be saved to a secure online webpage and then downloaded and saved to a password protected PC. The data will be stored for the duration of the study and for a total of seven years. After this time it will be permanently deleted.

What will happen if I don't want to carry on with the study? You are free to withdraw from the study at any time, for whatever reason. If you decide to take part in the study and then change your mind, you will be able to end the online questionnaire at any stage by closing the web page. If after completing the survey you wish to withdraw from the study, you can email the researcher your password and your responses will be removed. Please note, removal of responses cannot be guaranteed after 14 days as the data may have been used in the analysis and final results.

What will happen to the results of the research? After the study has been completed, it will be written up as part of the researcher's PhD project, and parts may be submitted for publication to an academic journal. If any of your responses from the questionnaires are used in the final doctoral thesis or related academic publications, pseudonyms will be used to maintain your anonymity. If you would like to receive a copy of the research summery at the end of the study, please contact the researcher by email.

Who is organising the research? The research is being organised by the University of Nottingham. Website: http://www.nottingham.ac.uk/

Who has reviewed the study? Ethical approval for this study has been granted by the University of Nottingham Medical School Ethics Committee.

Contact details

Researcher - Karen Louise Shepherd

Email - msxkls@nottingham.ac.uk

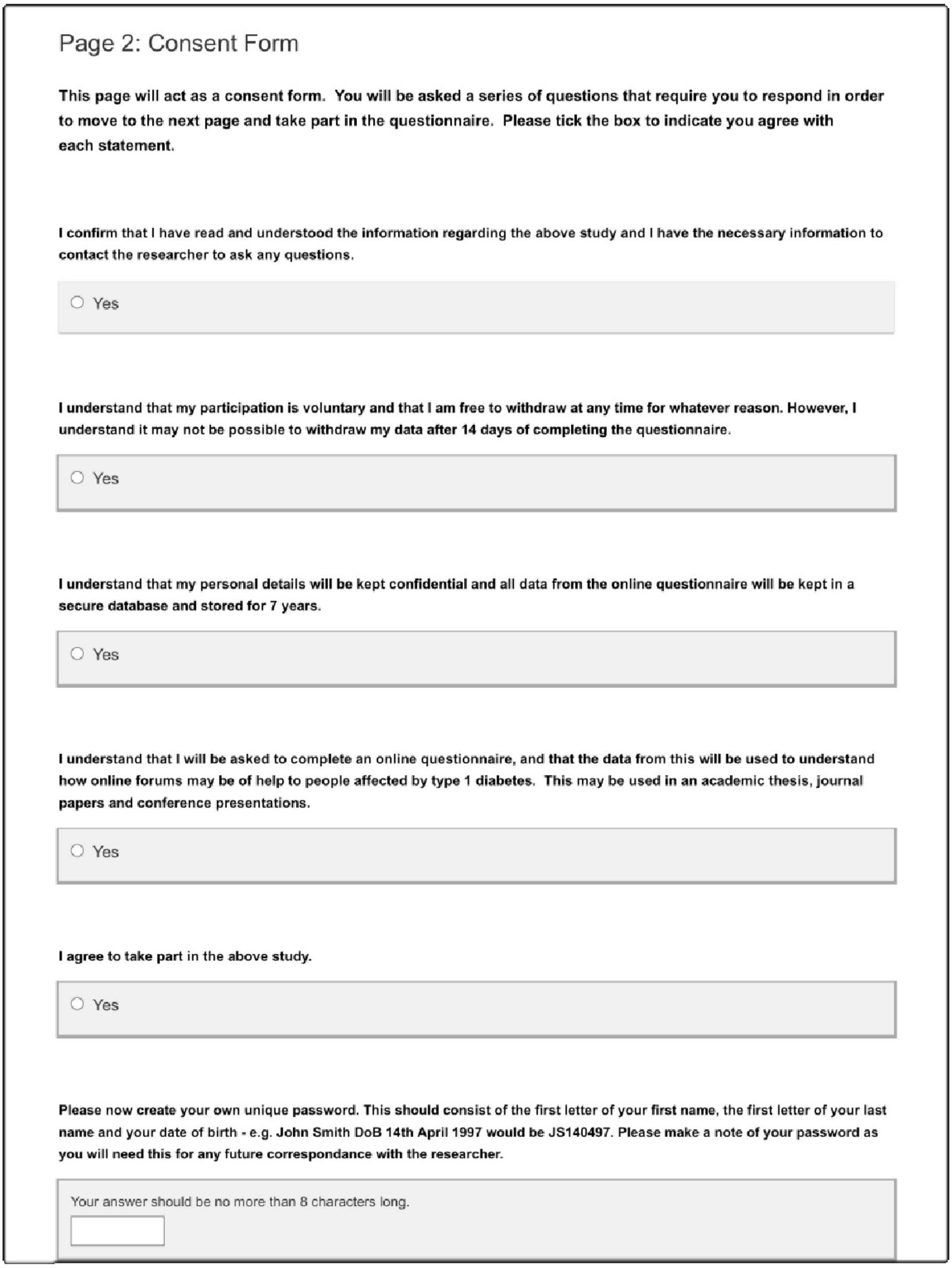
Supervisors -

Dr Neil Coulson

Email - neil.coulson@nottingham.ac.uk

Dr Heather Buchanan

Email – heather.buchanan@nottingham.ac.uk



Page 2: Consent Form

This page will act as a consent form. You will be asked a series of questions that require you to respond in order to move to the next page and take part in the questionnaire. Please tick the box to indicate you agree with each statement.

I confirm that I have read and understood the information regarding the above study and I have the necessary information to contact the researcher to ask any questions.

○ Yes

I understand that my participation is voluntary and that I am free to withdraw at any time for whatever reason. However, I understand it may not be possible to withdraw my data after 14 days of completing the questionnaire.

○ Yes

I understand that my personal details will be kept confidential and all data from the online questionnaire will be kept in a secure database and stored for 7 years.

○ Yes

I understand that I will be asked to complete an online questionnaire, and that the data from this will be used to understand how online forums may be of help to people affected by type 1 diabetes. This may be used in an academic thesis, journal papers and conference presentations.

○ Yes

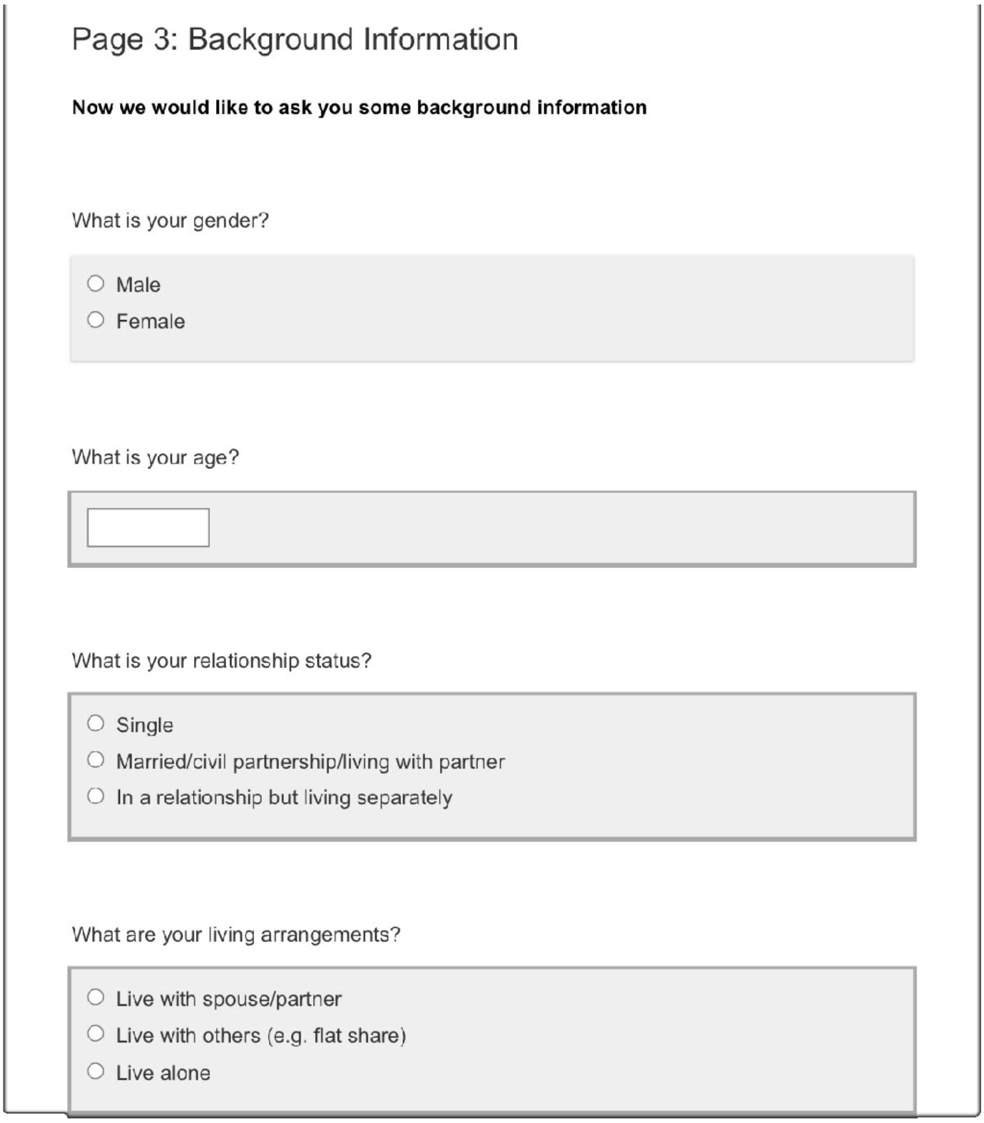
I agree to take part in the above study.

○ Yes

Please now create your own unique password. This should consist of the first letter of your first name, the first letter of your last name and your date of birth - e.g. John Smith DoB 14th April 1997 would be JS140497. Please make a note of your password as you will need this for any future correspondance with the researcher.

Your answer should be no more than 8 characters long.

☐



Page 3: Background Information

Now we would like to ask you some background information

What is your gender?

○ Male
○ Female

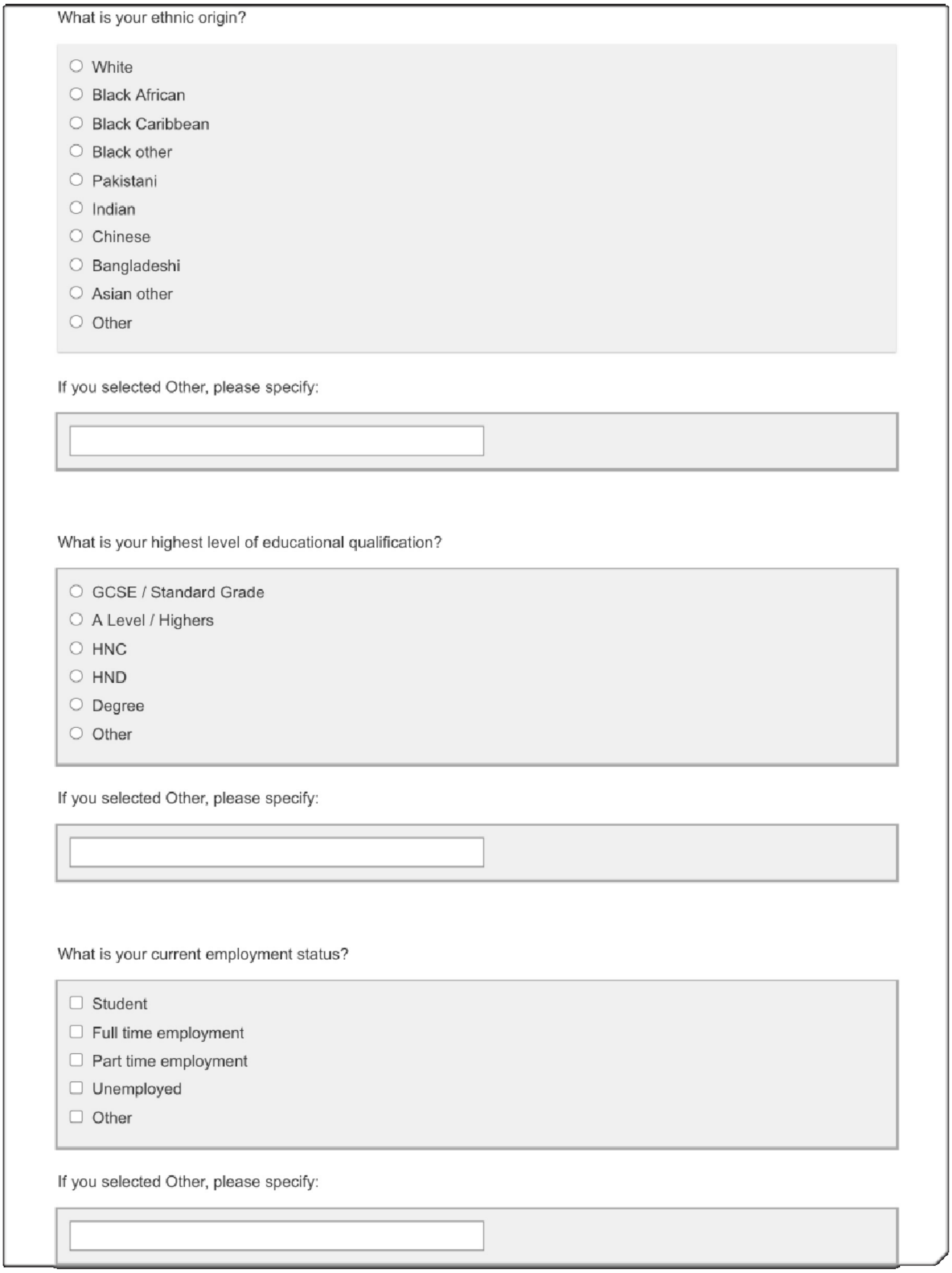
What is your age?

What is your relationship status?

○ Single
○ Married/civil partnership/living with partner
○ In a relationship but living separately

What are your living arrangements?

○ Live with spouse/partner
○ Live with others (e.g. flat share)
○ Live alone



What is your ethnic origin?

- ○ White
- ○ Black African
- ○ Black Caribbean
- ○ Black other
- ○ Pakistani
- ○ Indian
- ○ Chinese
- ○ Bangladeshi
- ○ Asian other
- ○ Other

If you selected Other, please specify:

What is your highest level of educational qualification?

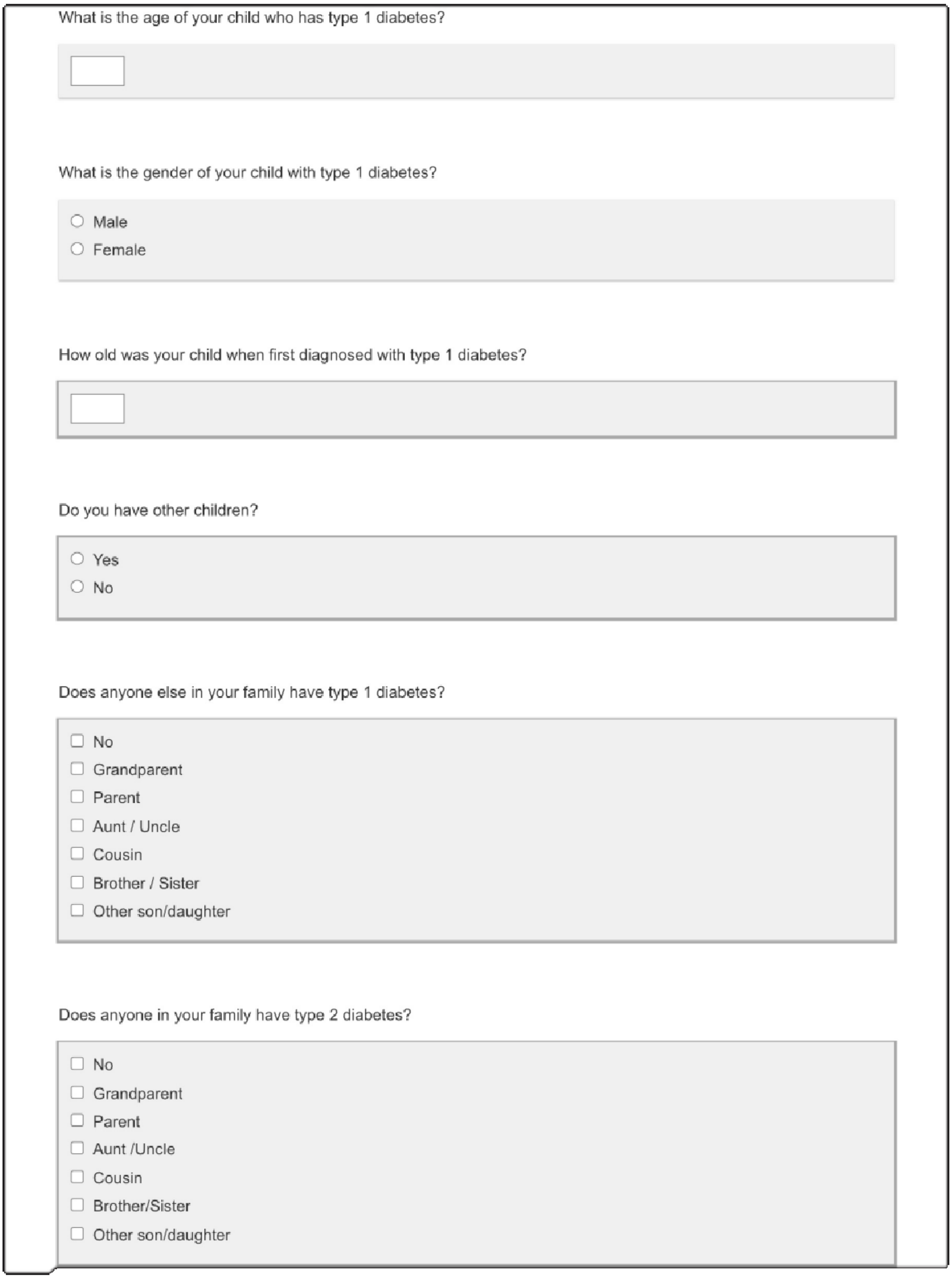
- ○ GCSE / Standard Grade
- ○ A Level / Highers
- ○ HNC
- ○ HND
- ○ Degree
- ○ Other

If you selected Other, please specify:

What is your current employment status?

- ☐ Student
- ☐ Full time employment
- ☐ Part time employment
- ☐ Unemployed
- ☐ Other

If you selected Other, please specify:



What is the age of your child who has type 1 diabetes?

What is the gender of your child with type 1 diabetes?

○ Male
○ Female

How old was your child when first diagnosed with type 1 diabetes?

Do you have other children?

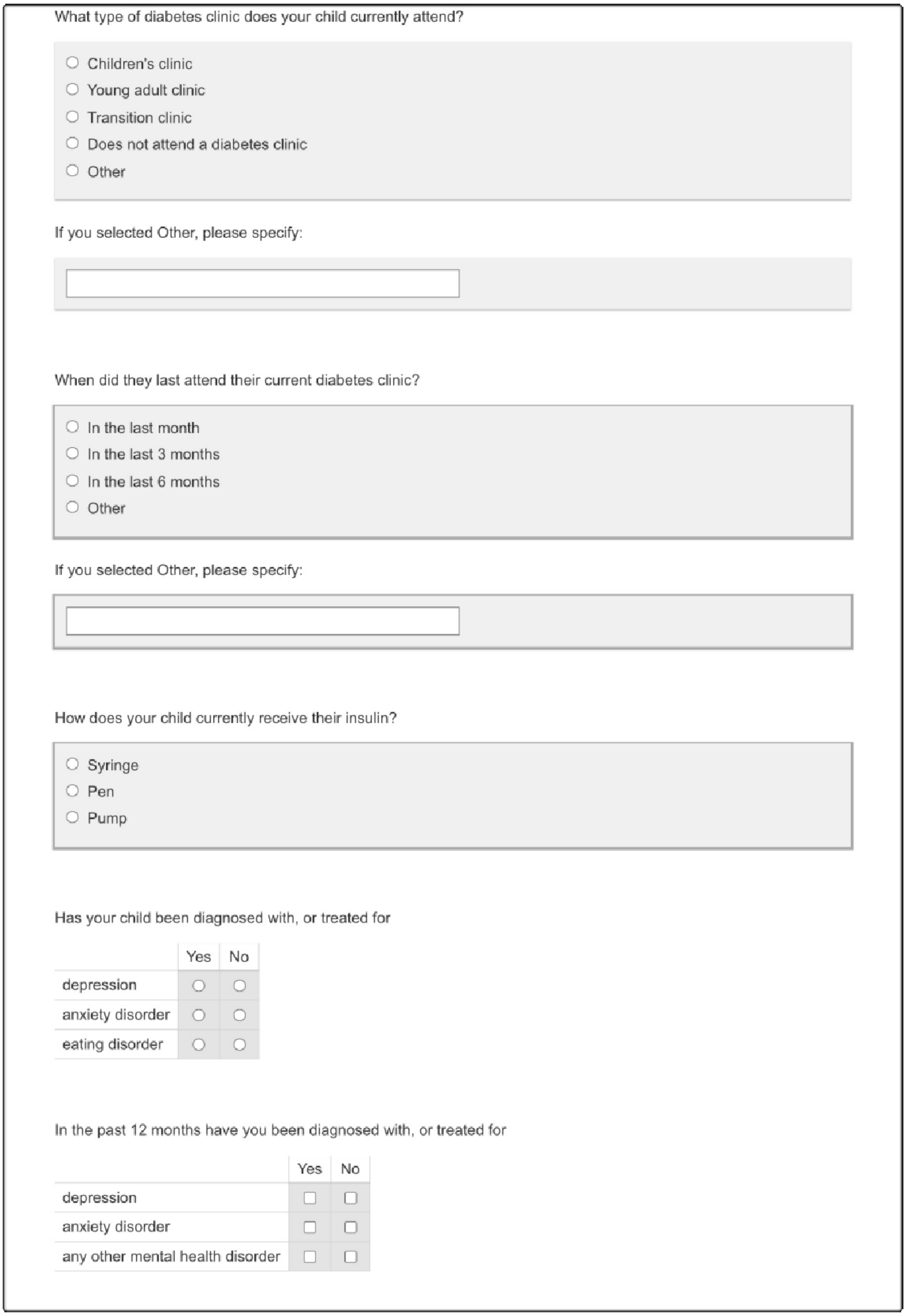
○ Yes
○ No

Does anyone else in your family have type 1 diabetes?

☐ No
☐ Grandparent
☐ Parent
☐ Aunt / Uncle
☐ Cousin
☐ Brother / Sister
☐ Other son/daughter

Does anyone in your family have type 2 diabetes?

☐ No
☐ Grandparent
☐ Parent
☐ Aunt /Uncle
☐ Cousin
☐ Brother/Sister
☐ Other son/daughter



What type of diabetes clinic does your child currently attend?

○ Children's clinic
○ Young adult clinic
○ Transition clinic
○ Does not attend a diabetes clinic
○ Other

If you selected Other, please specify:

When did they last attend their current diabetes clinic?

○ In the last month
○ In the last 3 months
○ In the last 6 months
○ Other

If you selected Other, please specify:

How does your child currently receive their insulin?

○ Syringe
○ Pen
○ Pump

Has your child been diagnosed with, or treated for

	Yes	No
depression	○	○
anxiety disorder	○	○
eating disorder	○	○

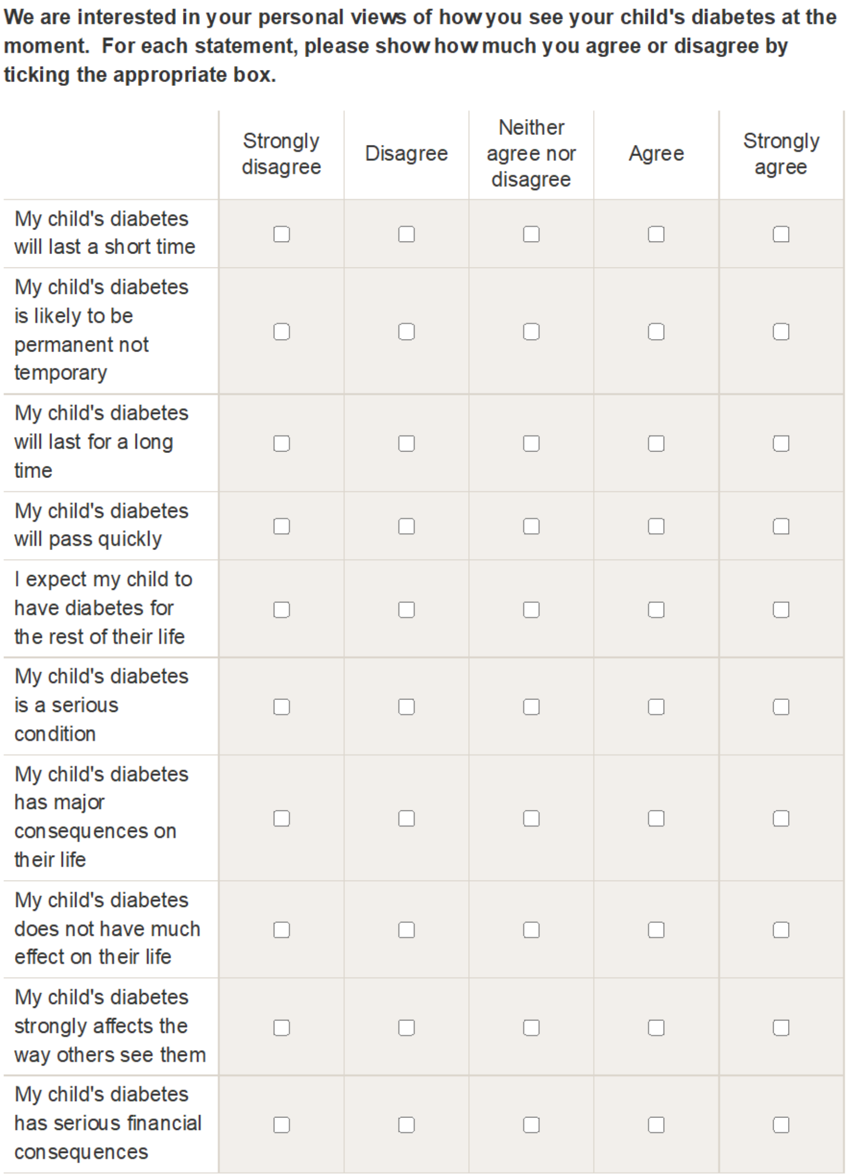
In the past 12 months have you been diagnosed with, or treated for

	Yes	No
depression	☐	☐
anxiety disorder	☐	☐
any other mental health disorder	☐	☐

Page 4: The following questions are about your thoughts and feelings about your child's diabetes. There are no right or wrong answers.

Listed below are a number of physical symptoms your child may or may not have experienced since being diagnosed with diabetes. Please show whether you know if they have had any of these since their diagnosis, and if you believe these were related to their diabetes by ticking 'Yes' or 'No'.

	My child has experienced this symptom since their diagnosis		This symptom is related to their diabetes	
	Yes	No	Yes	No
Pain	○	○	○	○
Sore throat	○	○	○	○
Nausea	○	○	○	○
Feeling breathless	○	○	○	○
Weight loss	○	○	○	○
Tiredness	○	○	○	○
Stiff joints	○	○	○	○
Sore eyes	○	○	○	○
Wheeziness	○	○	○	○
Headaches	○	○	○	○
Upset stomach	○	○	○	○
Difficulty sleeping	○	○	○	○
Dizziness	○	○	○	○
Physical weakness	○	○	○	○



We are interested in your personal views of how you see your child's diabetes at the moment. For each statement, please show how much you agree or disagree by ticking the appropriate box.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
My child's diabetes will last a short time	☐	☐	☐	☐	☐
My child's diabetes is likely to be permanent not temporary	☐	☐	☐	☐	☐
My child's diabetes will last for a long time	☐	☐	☐	☐	☐
My child's diabetes will pass quickly	☐	☐	☐	☐	☐
I expect my child to have diabetes for the rest of their life	☐	☐	☐	☐	☐
My child's diabetes is a serious condition	☐	☐	☐	☐	☐
My child's diabetes has major consequences on their life	☐	☐	☐	☐	☐
My child's diabetes does not have much effect on their life	☐	☐	☐	☐	☐
My child's diabetes strongly affects the way others see them	☐	☐	☐	☐	☐
My child's diabetes has serious financial consequences	☐	☐	☐	☐	☐

...personal views continued

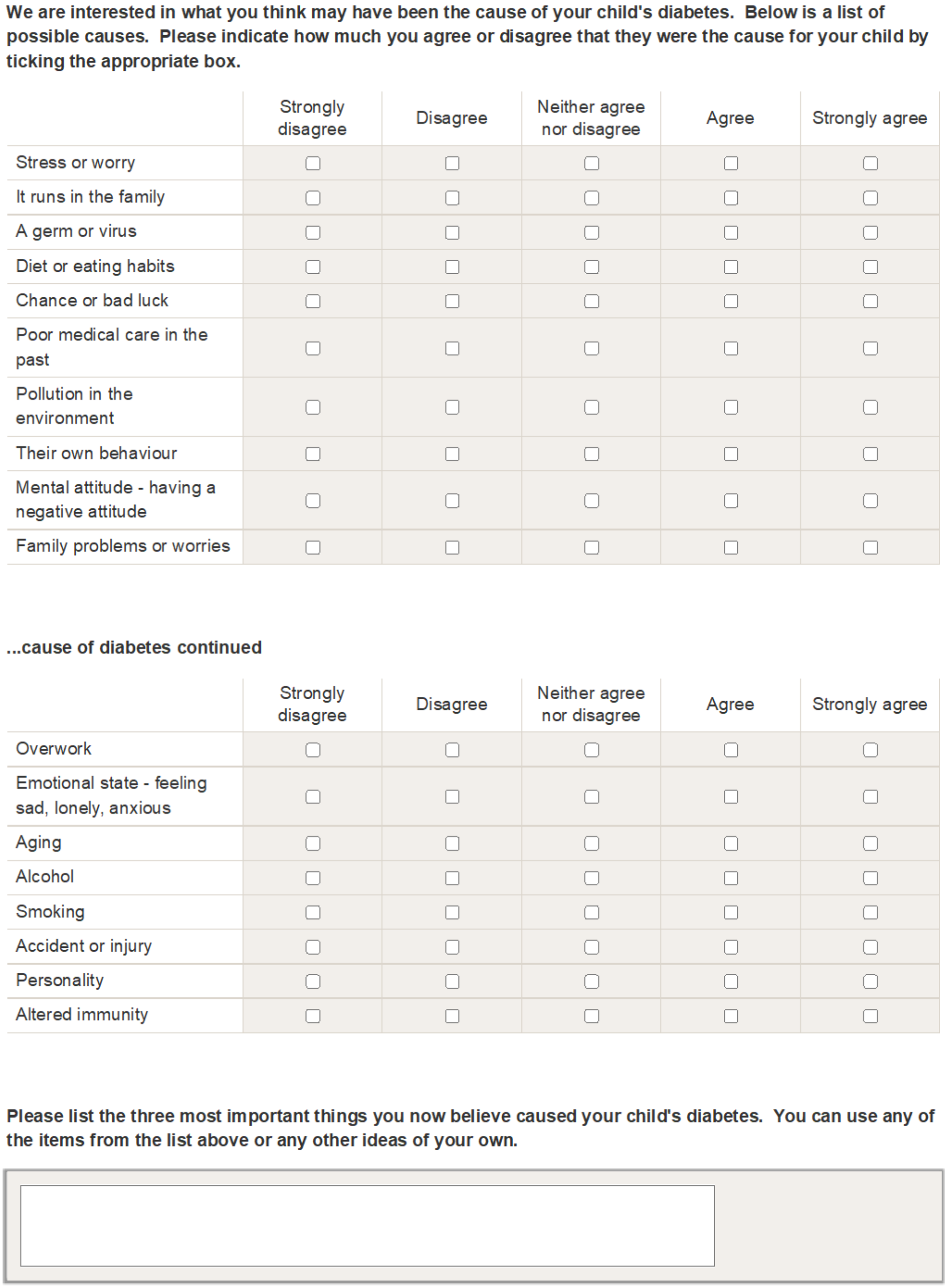
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
My child's diabetes causes problems for those who are close to them	☐	☐	☐	☐	☐
There is a lot I can do to control my child's symptoms	☐	☐	☐	☐	☐
What I do can determine whether my child's diabetes gets better or worse	☐	☐	☐	☐	☐
The course of my child's diabetes depends on me	☐	☐	☐	☐	☐
Nothing I do will affect my child's diabetes	☐	☐	☐	☐	☐
I have the power to influence my child's diabetes	☐	☐	☐	☐	☐
My actions will have no affect on the outcome of my child's diabetes	☐	☐	☐	☐	☐
My child's diabetes will improve in time	☐	☐	☐	☐	☐
There is very little that can be done to improve my child's diabetes	☐	☐	☐	☐	☐
My child's treatment will be effective in curing their diabetes	☐	☐	☐	☐	☐

...personal views continued

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The negative effects of my child's diabetes can be prevented or avoided by their treatment	☐	☐	☐	☐	☐
My child's treatment can control their diabetes	☐	☐	☐	☐	☐
There is nothing which can help my child's diabetes	☐	☐	☐	☐	☐
The symptoms of my child's diabetes are puzzling to me	☐	☐	☐	☐	☐
My child's diabetes is a mystery to me	☐	☐	☐	☐	☐
I don't understand my child's diabetes	☐	☐	☐	☐	☐
My child's diabetes doesn't make any sense to me	☐	☐	☐	☐	☐
I have a clear understanding of my child's diabetes	☐	☐	☐	☐	☐
The symptoms of my child's diabetes change a great deal from day to day	☐	☐	☐	☐	☐
My child's symptoms come and go in cycles	☐	☐	☐	☐	☐

...personal views continued

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
My child's diabetes is very unpredictable	☐	☐	☐	☐	☐
My child goes through stages when their diabetes gets better and worse	☐	☐	☐	☐	☐
I get depressed when I think about my child's diabetes	☐	☐	☐	☐	☐
When I think about my child's diabetes I get upset	☐	☐	☐	☐	☐
My child's diabetes makes me feel angry	☐	☐	☐	☐	☐
My child's diabetes does not worry me	☐	☐	☐	☐	☐
My child's diabetes makes me anxious	☐	☐	☐	☐	☐
My child's diabetes makes me feel afraid	☐	☐	☐	☐	☐



We are interested in what you think may have been the cause of your child's diabetes. Below is a list of possible causes. Please indicate how much you agree or disagree that they were the cause for your child by ticking the appropriate box.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Stress or worry	☐	☐	☐	☐	☐
It runs in the family	☐	☐	☐	☐	☐
A germ or virus	☐	☐	☐	☐	☐
Diet or eating habits	☐	☐	☐	☐	☐
Chance or bad luck	☐	☐	☐	☐	☐
Poor medical care in the past	☐	☐	☐	☐	☐
Pollution in the environment	☐	☐	☐	☐	☐
Their own behaviour	☐	☐	☐	☐	☐
Mental attitude - having a negative attitude	☐	☐	☐	☐	☐
Family problems or worries	☐	☐	☐	☐	☐

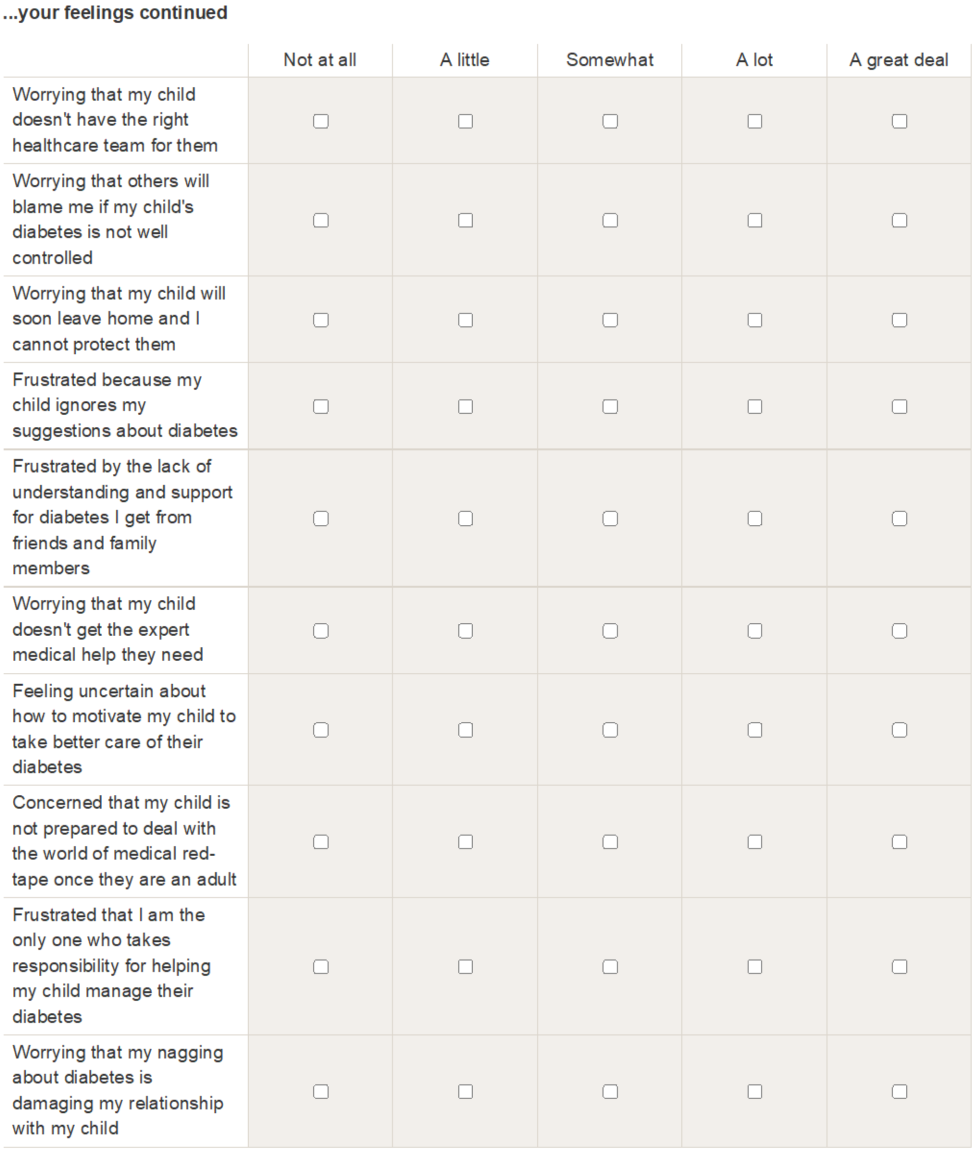
...cause of diabetes continued

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Overwork	☐	☐	☐	☐	☐
Emotional state - feeling sad, lonely, anxious	☐	☐	☐	☐	☐
Aging	☐	☐	☐	☐	☐
Alcohol	☐	☐	☐	☐	☐
Smoking	☐	☐	☐	☐	☐
Accident or injury	☐	☐	☐	☐	☐
Personality	☐	☐	☐	☐	☐
Altered immunity	☐	☐	☐	☐	☐

Please list the three most important things you now believe caused your child's diabetes. You can use any of the items from the list above or any other ideas of your own.

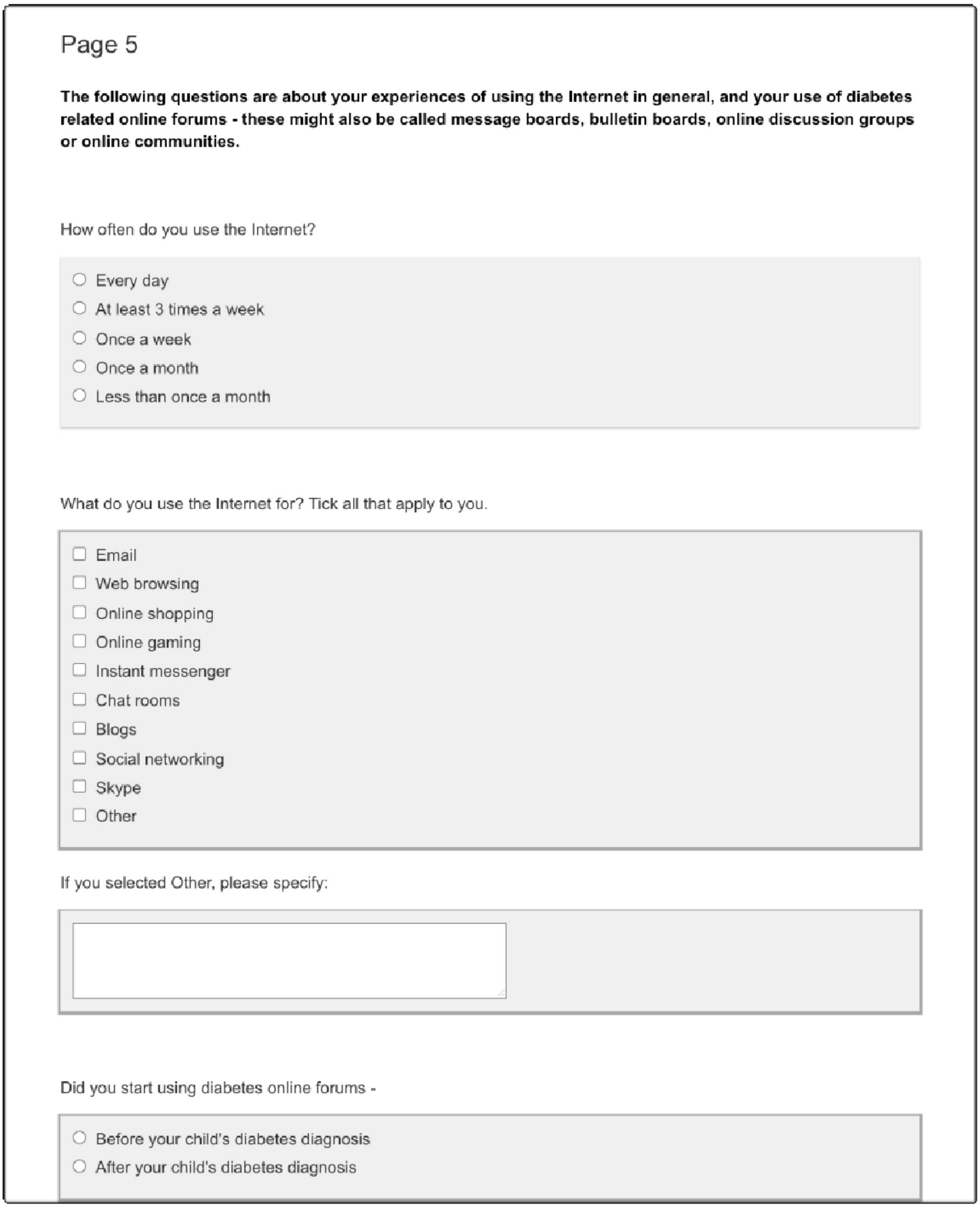
We are interested in how you have been feeling during the past month as the parent of a child with diabetes. Please say to what extent you agree with each statement.

	Not at all	A little	Somewhat	A lot	A great deal
Feeling that my child and I just don't work well together when it comes to diabetes	☐	☐	☐	☐	☐
Feeling unappreciated for all the ways I try to help my child to manage their diabetes	☐	☐	☐	☐	☐
Feeling that I can't trust my child to take good care of their diabetes	☐	☐	☐	☐	☐
Worrying about my child's low blood sugars when he/she is away from home	☐	☐	☐	☐	☐
Worrying that my child will ignore or forget about their diabetes if I don't keep reminding him/her	☐	☐	☐	☐	☐
Feeling that diabetes is taking up too much of my mental and physical energy every day	☐	☐	☐	☐	☐
Feeling that trying to help my child with their diabetes is always a battle	☐	☐	☐	☐	☐
Worrying about my child's low blood sugars when they are sleeping	☐	☐	☐	☐	☐
Feeling that no one notices that diabetes is hard on me, not just on my child	☐	☐	☐	☐	☐
Feeling that my child doesn't do enough to manage their diabetes	☐	☐	☐	☐	☐



...your feelings continued

	Not at all	A little	Somewhat	A lot	A great deal
Worrying that my child doesn't have the right healthcare team for them	☐	☐	☐	☐	☐
Worrying that others will blame me if my child's diabetes is not well controlled	☐	☐	☐	☐	☐
Worrying that my child will soon leave home and I cannot protect them	☐	☐	☐	☐	☐
Frustrated because my child ignores my suggestions about diabetes	☐	☐	☐	☐	☐
Frustrated by the lack of understanding and support for diabetes I get from friends and family members	☐	☐	☐	☐	☐
Worrying that my child doesn't get the expert medical help they need	☐	☐	☐	☐	☐
Feeling uncertain about how to motivate my child to take better care of their diabetes	☐	☐	☐	☐	☐
Concerned that my child is not prepared to deal with the world of medical red-tape once they are an adult	☐	☐	☐	☐	☐
Frustrated that I am the only one who takes responsibility for helping my child manage their diabetes	☐	☐	☐	☐	☐
Worrying that my nagging about diabetes is damaging my relationship with my child	☐	☐	☐	☐	☐



Page 5

The following questions are about your experiences of using the Internet in general, and your use of diabetes related online forums - these might also be called message boards, bulletin boards, online discussion groups or online communities.

How often do you use the Internet?

○ Every day
○ At least 3 times a week
○ Once a week
○ Once a month
○ Less than once a month

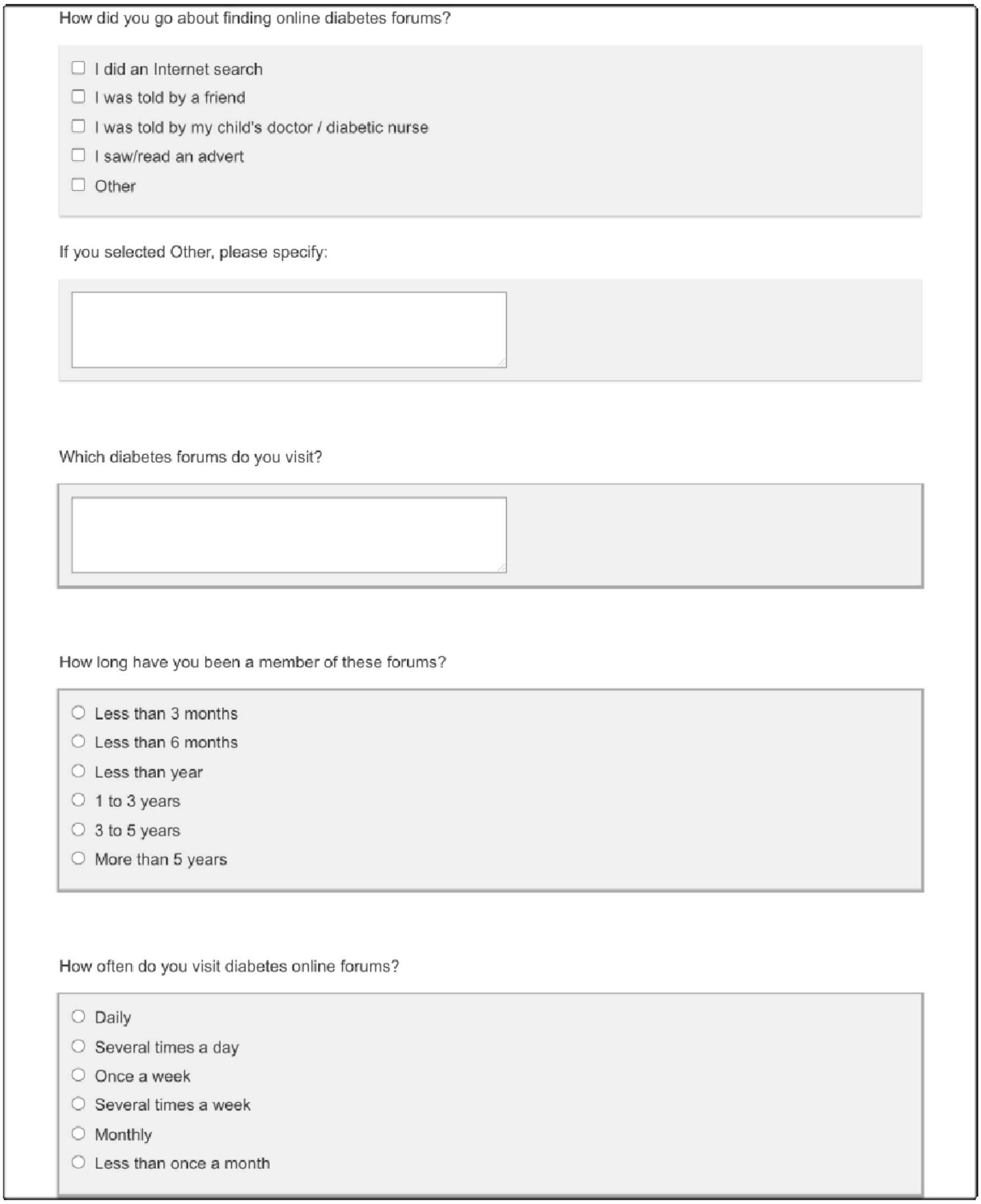
What do you use the Internet for? Tick all that apply to you.

☐ Email
☐ Web browsing
☐ Online shopping
☐ Online gaming
☐ Instant messenger
☐ Chat rooms
☐ Blogs
☐ Social networking
☐ Skype
☐ Other

If you selected Other, please specify:

Did you start using diabetes online forums -

○ Before your child's diabetes diagnosis
○ After your child's diabetes diagnosis



How did you go about finding online diabetes forums?

☐ I did an Internet search
☐ I was told by a friend
☐ I was told by my child's doctor / diabetic nurse
☐ I saw/read an advert
☐ Other

If you selected Other, please specify:

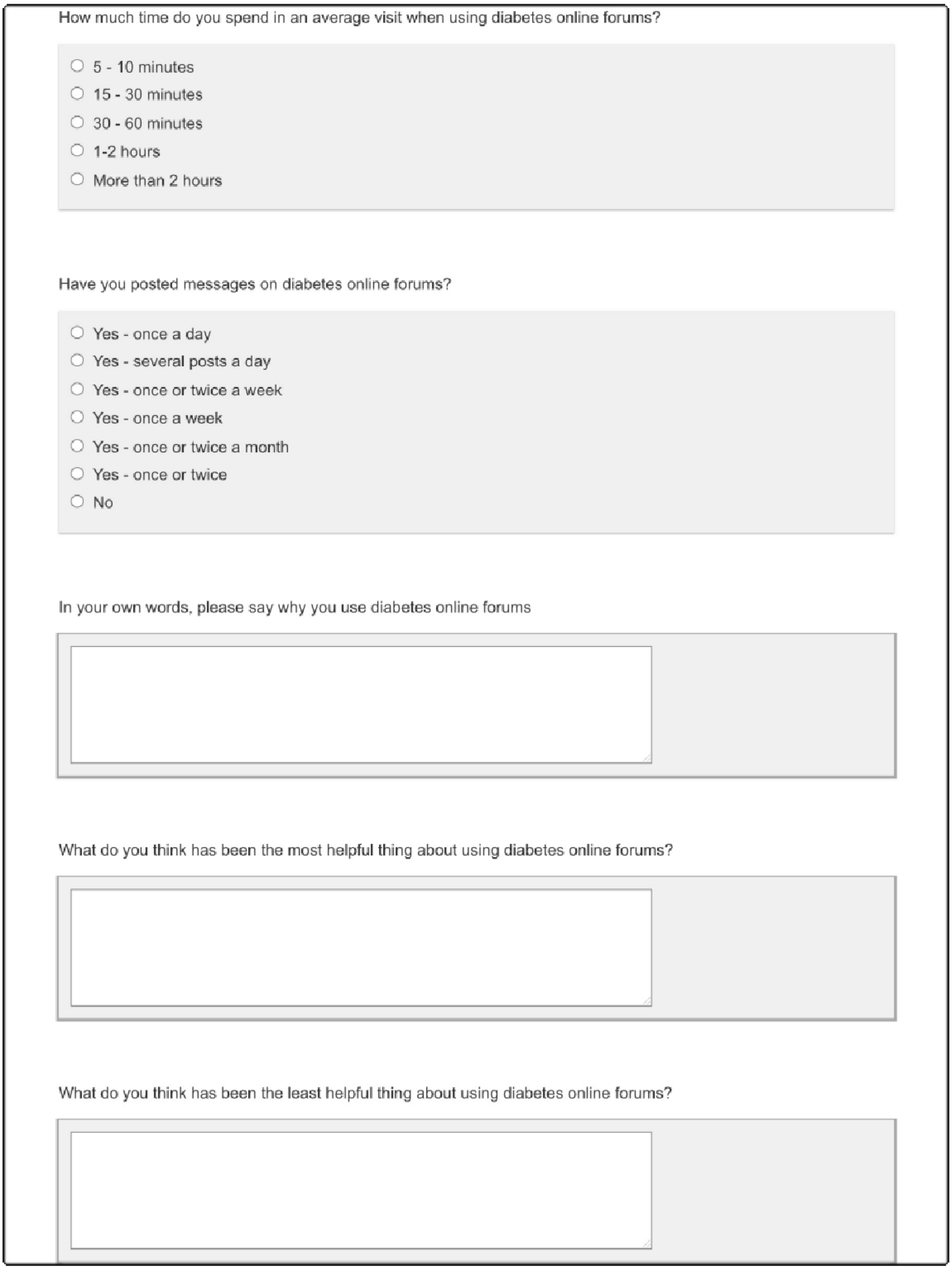
Which diabetes forums do you visit?

How long have you been a member of these forums?

○ Less than 3 months
○ Less than 6 months
○ Less than year
○ 1 to 3 years
○ 3 to 5 years
○ More than 5 years

How often do you visit diabetes online forums?

○ Daily
○ Several times a day
○ Once a week
○ Several times a week
○ Monthly
○ Less than once a month



How much time do you spend in an average visit when using diabetes online forums?

- ○ 5 - 10 minutes
- ○ 15 - 30 minutes
- ○ 30 - 60 minutes
- ○ 1-2 hours
- ○ More than 2 hours

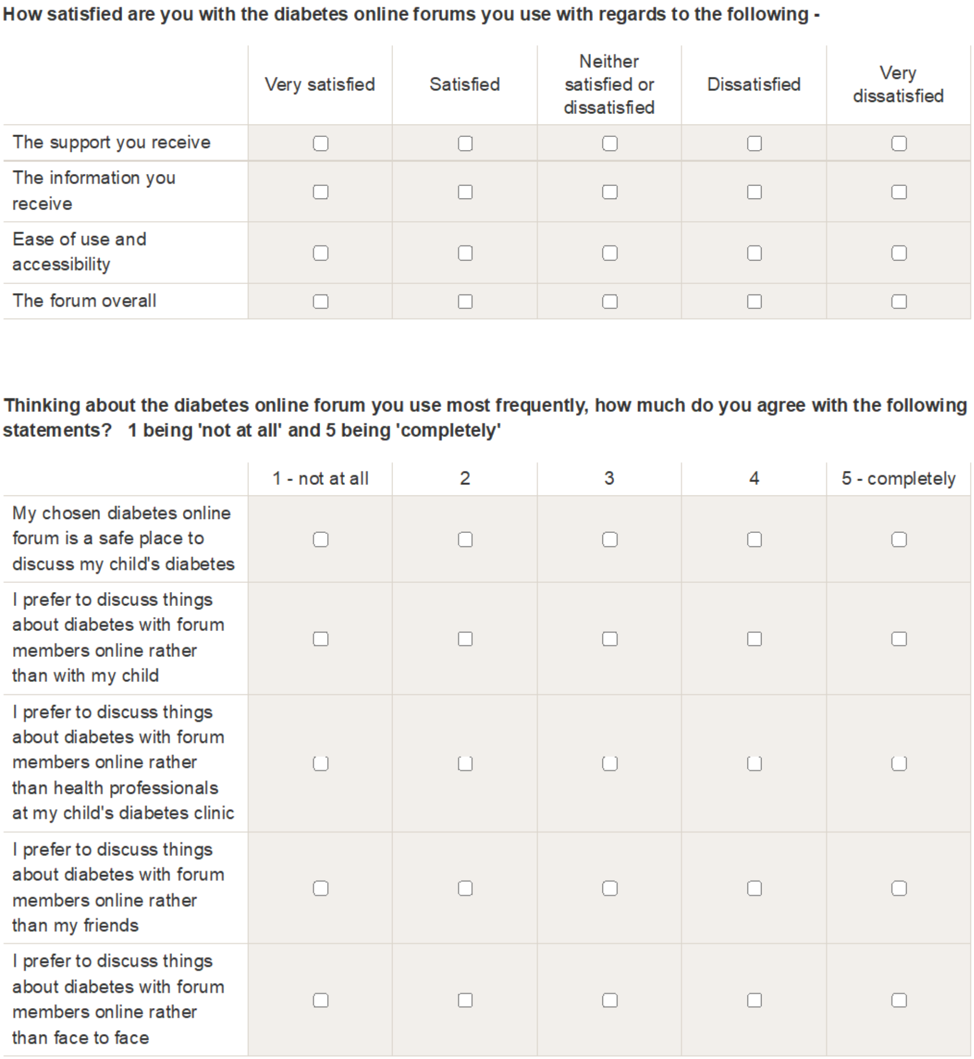
Have you posted messages on diabetes online forums?

- ○ Yes - once a day
- ○ Yes - several posts a day
- ○ Yes - once or twice a week
- ○ Yes - once a week
- ○ Yes - once or twice a month
- ○ Yes - once or twice
- ○ No

In your own words, please say why you use diabetes online forums

What do you think has been the most helpful thing about using diabetes online forums?

What do you think has been the least helpful thing about using diabetes online forums?



How satisfied are you with the diabetes online forums you use with regards to the following -

	Very satisfied	Satisfied	Neither satisfied or dissatisfied	Dissatisfied	Very dissatisfied
The support you receive	☐	☐	☐	☐	☐
The information you receive	☐	☐	☐	☐	☐
Ease of use and accessibility	☐	☐	☐	☐	☐
The forum overall	☐	☐	☐	☐	☐

Thinking about the diabetes online forum you use most frequently, how much do you agree with the following statements? 1 being 'not at all' and 5 being 'completely'

	1 - not at all	2	3	4	5 - completely
My chosen diabetes online forum is a safe place to discuss my child's diabetes	☐	☐	☐	☐	☐
I prefer to discuss things about diabetes with forum members online rather than with my child	☐	☐	☐	☐	☐
I prefer to discuss things about diabetes with forum members online rather than health professionals at my child's diabetes clinic	☐	☐	☐	☐	☐
I prefer to discuss things about diabetes with forum members online rather than my friends	☐	☐	☐	☐	☐
I prefer to discuss things about diabetes with forum members online rather than face to face	☐	☐	☐	☐	☐

In your experience of the diabetes online forum you use most frequently, would you say the information and advice exchanged is...

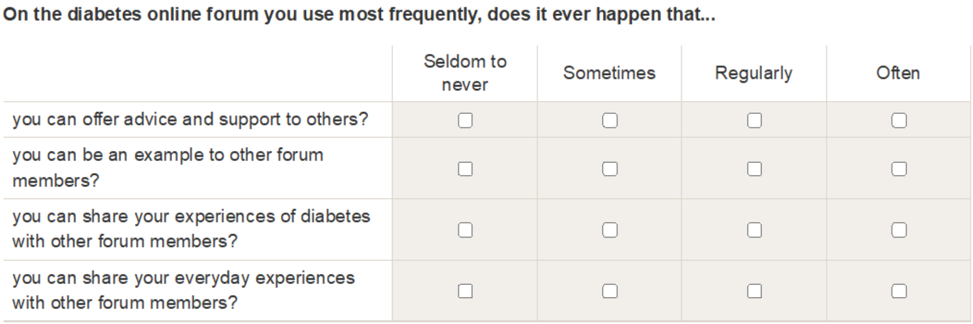
	Seldom to never	Sometimes	Regularly	Often
understandable	☐	☐	☐	☐
valuable	☐	☐	☐	☐
usable	☐	☐	☐	☐
new	☐	☐	☐	☐
applies to your present situation	☐	☐	☐	☐
reliable	☐	☐	☐	☐
correct	☐	☐	☐	☐
in line with the information I receive from my child's diabetes healthcare team	☐	☐	☐	☐
of added value to the information I receive from my child's diabetes healthcare team	☐	☐	☐	☐

How often does it happen that someone in the diabetes online forum you use most frequently....

	Seldom to never	Sometimes	Regularly	Often
invites you to have personal contact outside the forum?	☐	☐	☐	☐
starts a private conversation with you?	☐	☐	☐	☐
is empathetic?	☐	☐	☐	☐
consoles you?	☐	☐	☐	☐
pays you a compliment?	☐	☐	☐	☐
is interested in you?	☐	☐	☐	☐
pays particular attention to you in special cases, such as during an illness or a stressful time?	☐	☐	☐	☐
reassures you?	☐	☐	☐	☐
offers you sound advice?	☐	☐	☐	☐
points out your strengths?	☐	☐	☐	☐
confides in you?	☐	☐	☐	☐
asks you for your help or advice?	☐	☐	☐	☐

When you are viewing messages on the diabetes online forum you use most frequently, do you...

	Seldom to never	Sometimes	Regularly	Often
recognise yourself in the stories of other forum members?	☐	☐	☐	☐
experience a sense of 'not being the only one'?	☐	☐	☐	☐
feel other people are an example to you?	☐	☐	☐	☐
realise you are not so badly off after all?	☐	☐	☐	☐

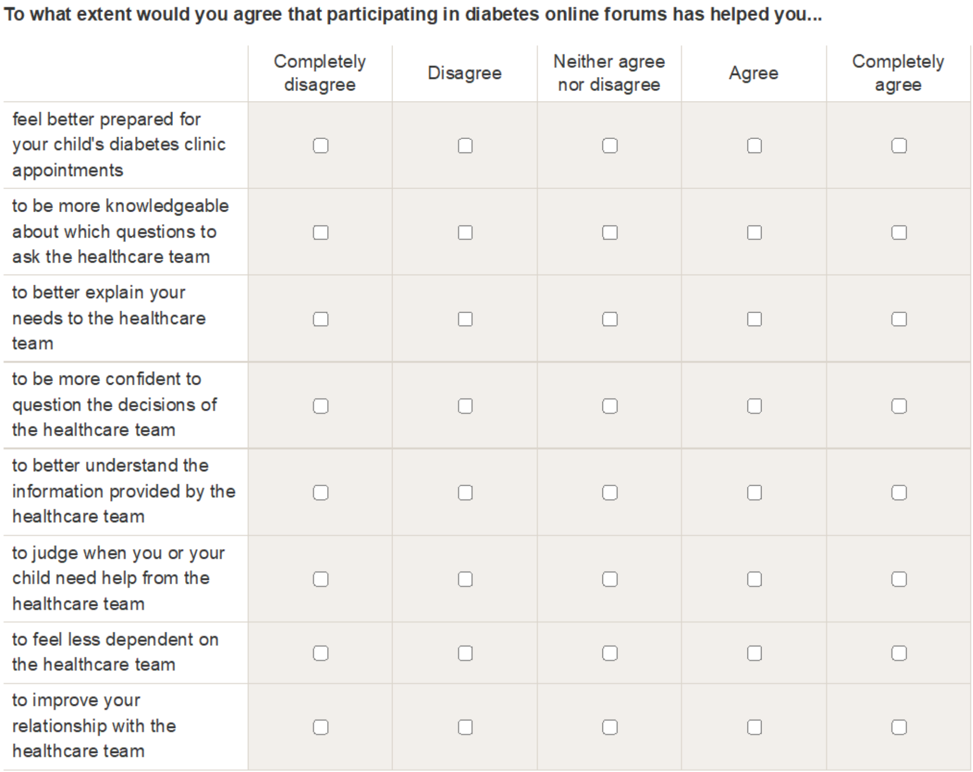


On the diabetes online forum you use most frequently, does it ever happen that...

	Seldom to never	Sometimes	Regularly	Often
you can offer advice and support to others?	☐	☐	☐	☐
you can be an example to other forum members?	☐	☐	☐	☐
you can share your experiences of diabetes with other forum members?	☐	☐	☐	☐
you can share your everyday experiences with other forum members?	☐	☐	☐	☐

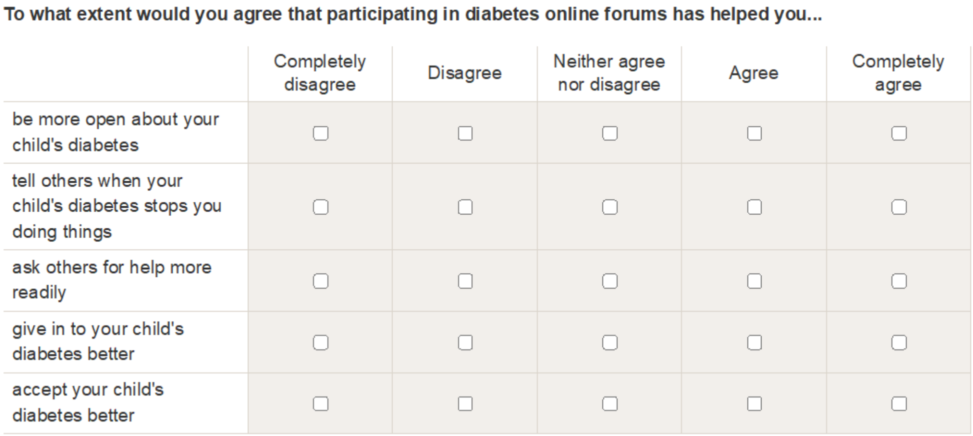
To what extent would you agree that participating in diabetes online forums has helped you to...

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
feel better informed as a parent of a child with diabetes	☐	☐	☐	☐	☐
understand your child's diabetes better	☐	☐	☐	☐	☐
have a clearer picture about treatment options in the future	☐	☐	☐	☐	☐
feel like you have more knowledge to help deal with your child's diabetes	☐	☐	☐	☐	☐



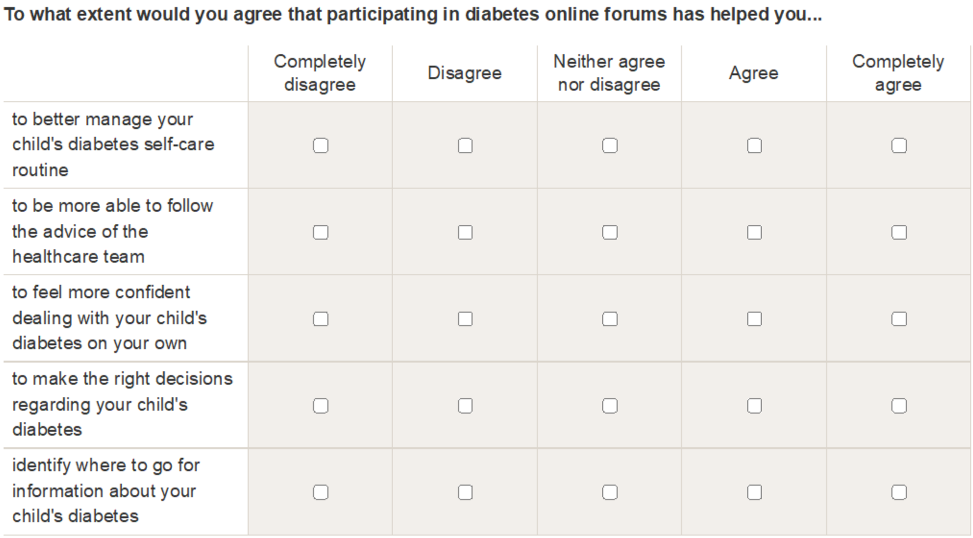
To what extent would you agree that participating in diabetes online forums has helped you...

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
feel better prepared for your child's diabetes clinic appointments	☐	☐	☐	☐	☐
to be more knowledgeable about which questions to ask the healthcare team	☐	☐	☐	☐	☐
to better explain your needs to the healthcare team	☐	☐	☐	☐	☐
to be more confident to question the decisions of the healthcare team	☐	☐	☐	☐	☐
to better understand the information provided by the healthcare team	☐	☐	☐	☐	☐
to judge when you or your child need help from the healthcare team	☐	☐	☐	☐	☐
to feel less dependent on the healthcare team	☐	☐	☐	☐	☐
to improve your relationship with the healthcare team	☐	☐	☐	☐	☐



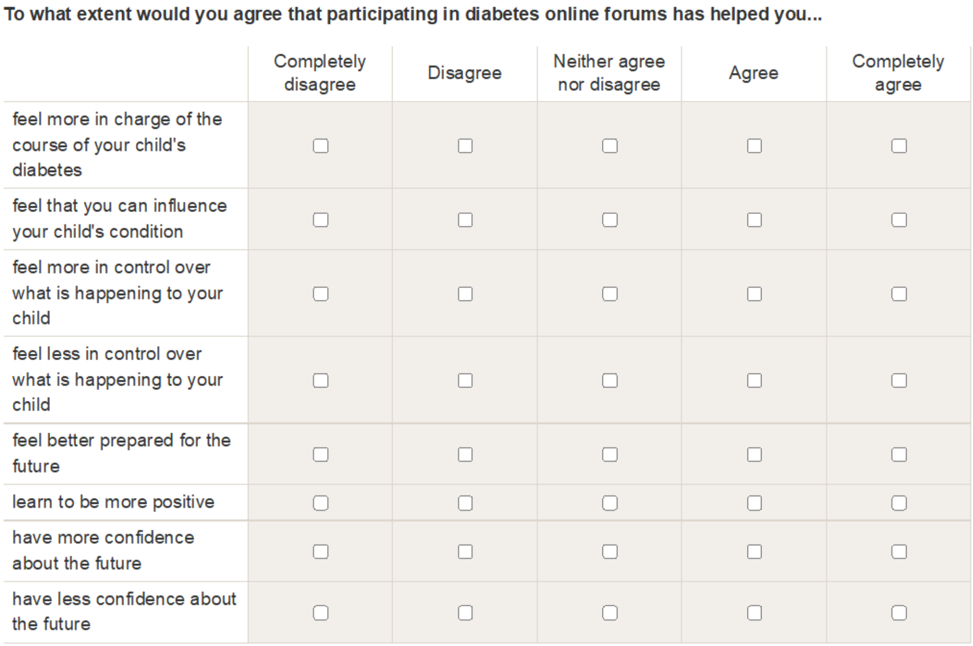
To what extent would you agree that participating in diabetes online forums has helped you...

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
be more open about your child's diabetes	☐	☐	☐	☐	☐
tell others when your child's diabetes stops you doing things	☐	☐	☐	☐	☐
ask others for help more readily	☐	☐	☐	☐	☐
give in to your child's diabetes better	☐	☐	☐	☐	☐
accept your child's diabetes better	☐	☐	☐	☐	☐



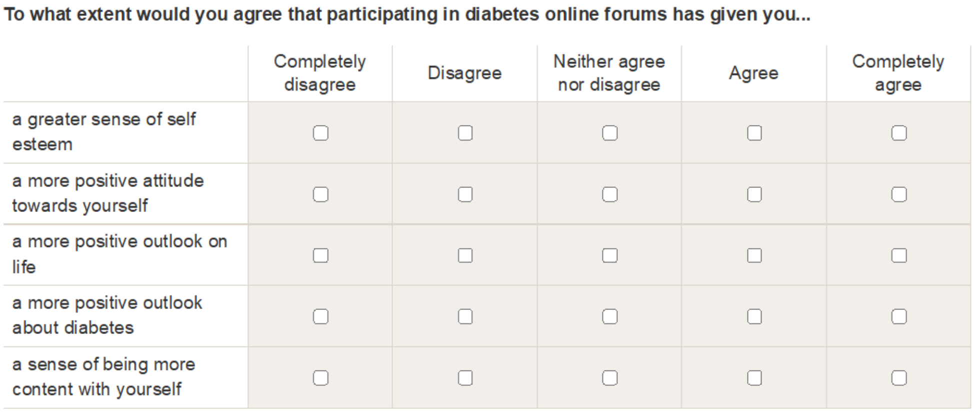
To what extent would you agree that participating in diabetes online forums has helped you...

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
to better manage your child's diabetes self-care routine	☐	☐	☐	☐	☐
to be more able to follow the advice of the healthcare team	☐	☐	☐	☐	☐
to feel more confident dealing with your child's diabetes on your own	☐	☐	☐	☐	☐
to make the right decisions regarding your child's diabetes	☐	☐	☐	☐	☐
identify where to go for information about your child's diabetes	☐	☐	☐	☐	☐



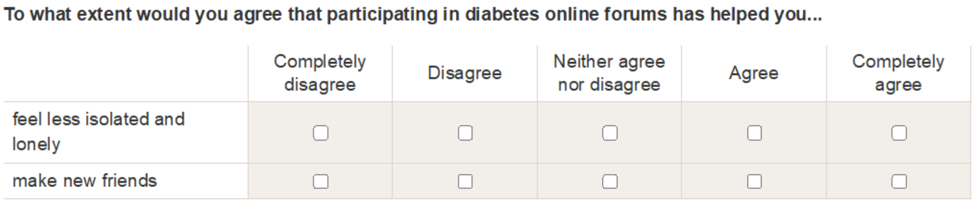
To what extent would you agree that participating in diabetes online forums has helped you...

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
feel more in charge of the course of your child's diabetes	☐	☐	☐	☐	☐
feel that you can influence your child's condition	☐	☐	☐	☐	☐
feel more in control over what is happening to your child	☐	☐	☐	☐	☐
feel less in control over what is happening to your child	☐	☐	☐	☐	☐
feel better prepared for the future	☐	☐	☐	☐	☐
learn to be more positive	☐	☐	☐	☐	☐
have more confidence about the future	☐	☐	☐	☐	☐
have less confidence about the future	☐	☐	☐	☐	☐



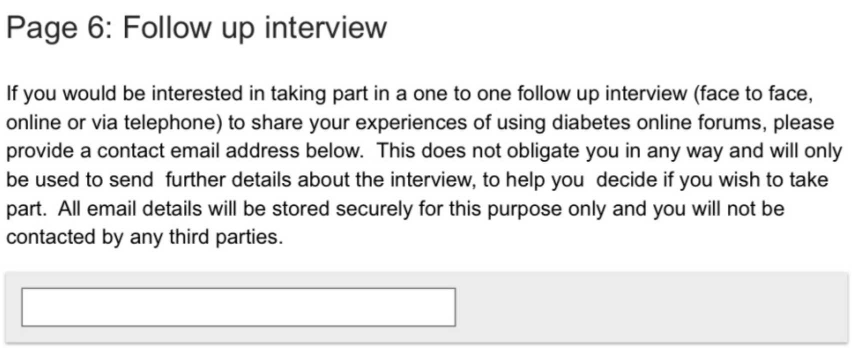
To what extent would you agree that participating in diabetes online forums has given you...

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
a greater sense of self esteem	☐	☐	☐	☐	☐
a more positive attitude towards yourself	☐	☐	☐	☐	☐
a more positive outlook on life	☐	☐	☐	☐	☐
a more positive outlook about diabetes	☐	☐	☐	☐	☐
a sense of being more content with yourself	☐	☐	☐	☐	☐



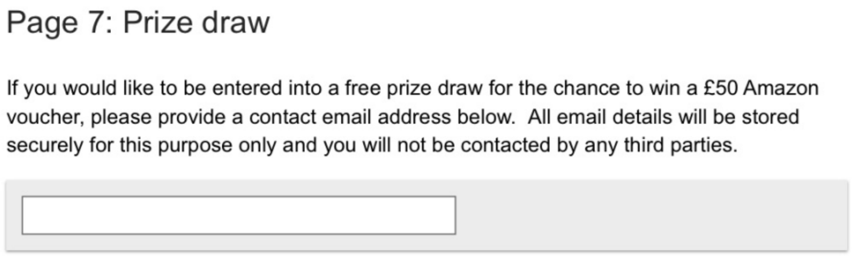
To what extent would you agree that participating in diabetes online forums has helped you...

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
feel less isolated and lonely	☐	☐	☐	☐	☐
make new friends	☐	☐	☐	☐	☐



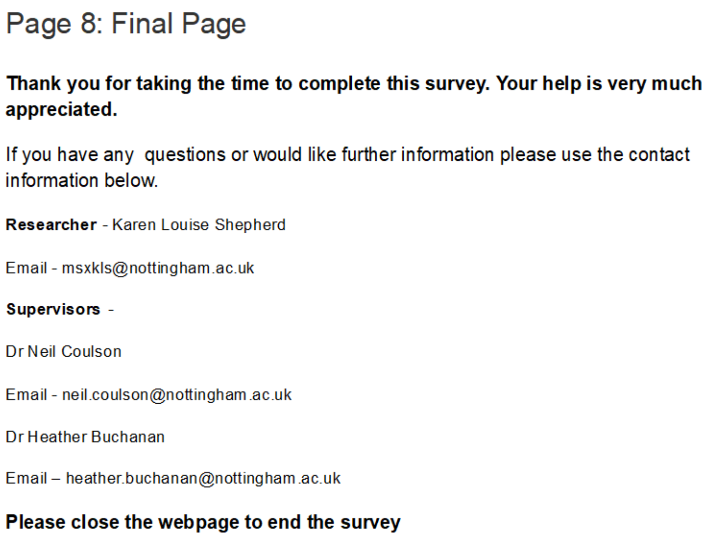
Page 6: Follow up interview

If you would be interested in taking part in a one to one follow up interview (face to face, online or via telephone) to share your experiences of using diabetes online forums, please provide a contact email address below. This does not obligate you in any way and will only be used to send further details about the interview, to help you decide if you wish to take part. All email details will be stored securely for this purpose only and you will not be contacted by any third parties.



Page 7: Prize draw

If you would like to be entered into a free prize draw for the chance to win a £50 Amazon voucher, please provide a contact email address below. All email details will be stored securely for this purpose only and you will not be contacted by any third parties.



Page 8: Final Page

Thank you for taking the time to complete this survey. Your help is very much appreciated.

If you have any questions or would like further information please use the contact information below.

Researcher - Karen Louise Shepherd

Email - msxkls@nottingham.ac.uk

Supervisors -

Dr Neil Coulson

Email - neil.coulson@nottingham.ac.uk

Dr Heather Buchanan

Email – heather.buchanan@nottingham.ac.uk

Please close the webpage to end the survey

Appendix C - Level of agreement with items of the empowering processes scale

Empowering processes scale item	Seldom to never %	Sometimes %	Regularly to often %
Exchanging information			
In your experience of the diabetes online forum you use most frequently would you say the information and advice exchanged is...			
understandable		10.2	89.8
valuable		13.6	86.4
new	3.4	52.3	44.3
applicable to my present situation		38.7	61.3
reliable		22.7	77.3
correct		25	75
in line with the information I receive from my child's diabetes healthcare team	1.1	38.6	60.3
of added value to the information I receive from my child's diabetes healthcare team	1.1	13.6	85.2
Encountering emotional support			
How often does it happen that someone in the diabetes online forum you use most frequently...			
invites you to have personal contact outside the forum?			
starts a private conversation with you?	47.7	43.2	9
is empathetic?	4.5	10.2	85.3
consoles you?	13.6	17	69.4
pays you a compliment?	19.3	36.4	44.3
is interested in you?	20.5	37.5	42
pays particular attention to you in special cases, such as during illness or a stressful time?	11.4	29.5	59.1
reassures you?	6.8	22.7	70.4
offers you sound advice?	4.5	15.9	79.5
points out your strengths?	21.6	28.4	50
confides in you?	29.5	33	37.5
asks you for your help or advice?	15.9	35.2	48.8
Finding recognition			
When you are viewing messages on the diabetes online forum you use most frequently, do you...			
recognise yourself in the stories of other forum members?	4.5	30.7	64.8
experience a sense of 'not being the only one'?	1.1	11.4	87.5

Empowering processes scale item	**Seldom to never %**	**Sometimes %**	**Regularly to often %**
feel that others are an example to you?	4.5	30.7	64.8
realise you are not so badly off after all?	4.5	42	53.5
Helping others			
On the diabetes online forum you use most frequently, does it ever happen that...			
you can offer advice and support to others?	3.4	47.7	48.9
you can be an example to other forum members?	9.1	54.5	36.3
Sharing experiences			
On the diabetes online forum you use most frequently, does it ever happen that...			
you can share your experiences of diabetes with other forum members?	4.5	30.7	64.8
you can share your everyday experiences with other forum members?	11.4	36.4	52.2
Finding a safe place			
Thinking about the diabetes online forum you use most frequently, how much do you agree with the following statements?	**Completely disagree or disagree %**	**Neither agree nor disagree %**	**Completely agree or agree %**
My chosen diabetes online forum is a safe place to discuss my child's diabetes	2.3	10.2	87.8
I prefer to discuss things about diabetes with forum members online rather than with my son/daughter	34.1	38.6	27.3
I prefer to discuss things about diabetes with forum members online rather than health professionals at my child's diabetes clinic	45.4	36.4	18.1
I prefer to discuss things about diabetes with forum members online rather than my friends	11.4	9.1	79.5
I prefer to discuss things about diabetes with forum members online rather than face to face	25	13.6	61.4

Appendix D - Level of agreement with items of the empowering outcomes scale

Empowering outcomes scale item	Completely disagree or disagree %	Neither agree nor disagree %	Completely agree or agree %
Being better informed			
Participating in diabetes online forums has helped you to...			
feel better informed as a parent of a child with diabetes	3.4	8	88.6
have a clearer picture about treatment options in the future	3.3	20.5	76.2
feel like you have more knowledge to help deal with your child's diabetes	4.5	10.2	85.3
Feeling more confident in the relationship with child's healthcare team			
Participating in diabetes online forums has helped you...			
to better explain your needs to the healthcare team	21.6	19.3	59.1
to better understand the information provided by the healthcare team	21.6	18.2	60.2
to feel less dependent on the healthcare team	30.6	20.5	48.9
to improve your relationship with the healthcare team	28.4	40.9	30.7
Improved acceptance of the illness			
Participating in diabetes online forums has helped you...			
be more open about your child's diabetes	9.1	34.1	56.8
tell others when your child's diabetes stops you doing things	17	33	50
ask others for help more readily	18.2	35.2	46.6
give in to your child's diabetes better	27.3	51.1	21.5
accept your child's diabetes better	14.8	34.1	51.1
Feeling more confident about the treatment			
Participating in diabetes online forums has helped you...			
to better manage your child's diabetes self-care regime	14.7	25	60.3

Empowering outcomes scale item	Completely disagree or disagree %	Neither agree nor disagree %	Completely agree or agree %
to be more able to follow the advice of the healthcare team	28.5	40.8	30.7
to feel more confident dealing with your child's diabetes on your own	13.7	17	69.3
to make the right decisions regarding your child's diabetes	14.7	14.8	70.5
identify where to go for information about your child's diabetes	7.9	11.4	80.7
Increased optimism and control over the future			
Participating in diabetes online forums has helped you...			
feel more in charge of the course of your child's diabetes	17.1	27.3	55.6
feel that you can influence your child's condition	18.2	29.5	52.3
feel more in control about what is happening to your child	15.8	27.3	56.9
feel less in control about what is happening to your child	72.8	23.9	3.3
feel better prepared for the future	12.5	21.5	66
learn to be more positive	9.1	27.2	63.7
have more faith in the future	10.2	33	56.8
have less faith in the future	63.7	30.7	5.6
Enhanced self-esteem			
Participating in diabetes online forums has helped you...			
a greater sense of self worth	18.2	37.5	44.3
a more positive outlook on life	18.2	39.8	42
a more positive outlook about diabetes	12.5	28.4	59.1
a sense of being more content with yourself	20.5	50	29.5
Enhanced social well-being			
Participating in diabetes online forums has helped you...			
feel less isolated and lonely	7.9	10.2	81.9
make new friends	15.9	31.8	52.3

Appendix E: Study 2 information sheet and consent form

Exploring the role of online support groups for parents of adolescents with type 1 diabetes during the transition from paediatric to adult diabetes services.

Participant Information Sheet

Principle Researcher - Karen Louise Shepherd

We would like to invite you to participate in a follow up one to one interview as part of the research study you recently took part in by completing an online questionnaire. Before you decide to take part, it is important that you understand the purpose of the study and what is involved.

What is the purpose of the study?
This study is being carried out as part of a PhD in Health Psychology in the School of Medicine at the University of Nottingham. The purpose of this study is to examine how parents of adolescents with type 1 diabetes use diabetes online support groups for information and social support during a period of change. It will look at the impact online support groups have for individuals as well as the positive or negative aspects of group membership.

What will happen to me if I decide to take part?
Participation is completely voluntary and you are under no obligation to take part. Participating in this part of the study involves a one to one interview with the principle researcher, Karen Shepherd. If after reading the information sheet you would like to take part, please complete the consent form that was sent to you and return it via email. A convenient time and place will be arranged to conduct the interview, which should last between 30-45 minutes and will be recorded. The questions will be about your thoughts and experiences of using diabetes online support groups. If there are any questions you find uncomfortable or do not wish to answer please tell the researcher, and you can pause or end the interview at any time. It is not expected there will be any disadvantage in taking part in the study, and the interview should not cause any distress or anxiety, as it will deal with familiar topics.

What are the possible benefits of taking part?
The results from this research will help provide more information about how online support groups are used by people affected by type 1 diabetes, and consider how these resources could be developed to benefit more people in the future.

Will my taking part in the study be kept confidential?
All data will be collected anonymously and stored securely. All recorded information will be kept in MP3 format on a password protected external hard drive that only the research team will have access to. The data will be stored for the duration of the study and for a total of seven years. After this time it will be permanently deleted.

What will happen if I don't want to carry on with the study?
You are free to withdraw from the study at any time, for whatever reason. If you decide to take part in the interview and then change your mind, you can end the interview at any time by asking the principle researcher to stop.

What will happen to the results of the research?
After the study has been completed, it will be written up as part of the principle researcher's PhD project and parts may be submitted for publication to an academic journal. If any of your responses from the interview are used in the final doctoral thesis or related academic publications, pseudonyms will be used to maintain your anonymity. If you would like to receive a copy of the research summery at the end of the study, please contact the researcher by email.

Who is organising the research?
The research is being organised by the University of Nottingham, and ethical approval for this study has been granted by the University of Nottingham Medical School Ethics Committee.
Website: http://www.nottingham.ac.uk/

What if there is a problem?
If you have any queries or concerns about the study, or would like any further information, please contact the principle researcher or the researcher's supervisor using the contact details at the end of this information sheet.

Contact details
Principle Researcher - Karen Louise Shepherd
Email - msxkls@nottingham.ac.uk

Supervisors - Dr Neil Coulson
Email - neil.coulson@nottingham.ac.uk

Dr Heather Buchanan
Email – heather.buchanan@nottingham.ac.uk

Consent Form

Please tick the box to indicate you agree with the statements and return the completed form by email to the principle researcher Karen Shepherd - mailto:msxkls@nottingham.ac.uk

- I confirm that I have read and understood the information sheet regarding the above study and I have the necessary information to contact the principle researcher to ask any questions.

  YES ☐

- I understand that I will be asked to participate in a one to one interview with the principle researcher and this will be recorded.

  YES ☐

- I understand that my participation is voluntary and that I am free to withdraw at any time during the interview for whatever reason.

  YES ☐

- I understand that I have the right to withdraw from this study after completing the interview without consequence by e-mailing the principle researcher and asking for my responses to be removed.

  YES ☐

- I understand that my personal details will be kept confidential and all data from the interview will be kept in a secure password protected external hard drive and stored for 7 years.

  YES ☐

- I agree that information or quotes from my responses can be used in the final PhD thesis and subsequent publications, and I understand that all information and quotes will be completely anonymised.

  YES ☐

- I understand that this research has received ethical approval from the University of Nottingham Medical School Ethics Committee.

  YES ☐

- I agree to take part in the above study.

  YES ☐

Appendix F: Interview guide for one-to-one interviews for Study 2

Introduction -

- Ask participants to confirm their details and verbally give their informed consent
- Icebreaker questions

Type 1 diabetes -

- Could you describe the circumstances that led up to your son/daughters diagnosis of type 1 diabetes (for parents)
- Could you describe the circumstances that led up to your diagnosis of type 1 diabetes (for adolescents)
- Did you have any prior knowledge or experience of diabetes (type 1 or 2)?
- How did you manage dealing with the diagnosis?
- Where did you get support from?
- How supportive were your family?
- How understanding were your friends?
- How supportive where the health professionals you came into contact with?
- Was there any type of support you feel you needed after diagnosis but did not receive, and from whom?

Using diabetes online support groups (OSG) -

- Could you describe how you generally use the Internet on a daily basis
- When did you first access OSG's, prior or post diagnosis?
- Which diabetes online support groups do you use?
- How did you find the OSG's?
- Did you join the group or just read messages (lurk)?
- Did you choose to join a private group rather than an open group? Why? What are the advantages/disadvantages?
- How long have you been a member of the OSG you use most frequently?
- Why do you prefer this group over others you have viewed/joined?
- What are the benefits of a diabetes specific OSG?
- Are there any disadvantages to a diabetes OSG?
- What do you like about the group you use most frequently?
- What do you dislike about the group you use most frequently?
- Is there anything you would change about the groups you use most frequently?
- Do you feel welcome in the OSG's you use?
- Do you feel comfortable engaging with other group members?
- Do you offer advice to others?
- Do you ever correct the information that other members post on OSG's?
- Have you ever felt bullied on OSG’s? What did you do?
- Have you ever left a group? Why?
- Do you ever get angry about the content on OSG's?
- Are you scared by what you read on OSG's? What effect does this have on you?
- Have any of the health professionals you have contact with recommended OSG's? Which?
- Has accessing OSG's had an effect on your (or child’s) diabetes management?
- Has your physical health improved after using OSG's? How? Why?
- Has your mental health improved after using OSG's How? Why?

Posting messages

- How often do you post messages on OSG's?
- Do you start threads or respond to other members’ messages?
- When you start a thread what kinds of issues/topics is it about?
- Do you feel comfortable/confident to start a message thread? If not why?
- Do replies from other members encourage you to post more often?
- Have you ever deleted messages you posted? Why?
- Do you 'like' messages? Why?
- What are the benefits of posting messages on OSG's?
- Are there any disadvantages to posting messages?
- Do you post more messages asking for advice or offering advice? Why?
- Have you ever sent another member a private message (PM) or received a PM?
- Why would you use PM's?
- Have you ever received a PM that made you uncomfortable or offered unsolicited advice? How did you respond?
- Have you ever had cause to contact the OSG's administrators? For what reason?
- Have you reported other members to the OSG's administrators? Why? What was the outcome?

General questions about OSG's

- How easy was it to start using OSG's? Did you need any specific computer skills? Did this dissuade you from using an OSG?
- How long do you think you will continue to use OSG's? Why?
- Have you ever recommended an OSG you use to another person?
- How much time do you spend using OSG's? Does this have an impact on your daily life or your relationship with other people not on the OSG?
- How would you describe the other people on the OSG? Friend/member?
- Have you ever met other OSG members face to face? In what circumstance? How was the experience?
- How much humour is there on the OSG's you use? Is this important?
- How much do you think you have learnt about type 1 diabetes from using OSG's? Is it more or less than you anticipated?
- Have you set up your own OSG? Would you like to? What would you include/exclude?
- Have you experienced any bullying on an OSG? How did you react? What was the outcome?
- Are you more patient/less patient with other members of OSG's in comparison to people you know offline? Why do you think that is the case?

Debrief -

- Thank each participant for taking part in the interview.
- Ask if they have any questions about the research.
- Check they have the contact details of all the researchers.
- Ask if they would like a precis of the thesis.