Stress and Coping in Parents of Children with Developmental Disabilities and the Development of a Brief Coping Intervention

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DECLARATION SHEET

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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STATEMENT 1

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"As we express our gratitude, we must never forget that the highest appreciation is not to utter words, but to live by them". John F Kennedy

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ABSTRACT

Caring for a child diagnosed with a developmental disability adds extra parenting responsibilities in addition to the typical day to day caring duties parents have towards their child. Research suggests that parents caring for a child with a developmental disability may experience higher levels of stress in comparison to parents of typically developing children and an appropriate coping intervention may aid in reducing this stress. The main aim of this thesis was to understand the process of stress and coping in parents of children with developmental disabilities and to develop a theory based brief coping intervention which may help them to cope with their day to day stress. An additional aim was to evaluate the impact of the usage of the self-help coping leaflet on the parents' stress and coping behaviours. This thesis was mainly located within the transactional model of stress and coping the Double ABCX model of family stress, focusing on the theoretical position that any alteration in the cognitive appraisal can change the orientation of coping behaviours thereby resulting in a change to the stress response. This research study combined both qualitative and quantitative research methods structured around the intervention development framework as outlined by the Medical Research Council (MRC, 2000).

Study One was a qualitative study analysing the subjective experience of stress and coping in parents of children diagnosed with developmental disabilities and followed the Pre-clinical phase of intervention development, to explore relevant theory, to ensure the choice of the intervention and identify its components (MRC, 2000). The parents participating in this study reported a prevalence of high stress and the use of varied array of coping styles along with positive emotions surrounding their caring role.

Studies Two (Phase I) and Three (Phase II) were exploratory in nature, aiming to evaluate the intervention in order to obtain evidence to identify appropriate outcome measures, estimates for recruitment and to support the theoretically expected effect of the intervention as outlined by the Medical Research Council guidelines for developing complex interventions (MRC, 2000). Study Two was a pilot study conducted with the aim to assess the acceptability and feasibility of the self-help coping leaflet which was designed as a coping intervention. The analysis of this study revealed that coping leaflet may be an effective tool in minimising levels of stress and enhancing coping effectiveness amongst parents.

Study Three was an exploratory longitudinal within subjects study designed to assess the effectiveness of the self-help coping intervention. The results of this study provide encouraging evidence suggesting that such an intervention can be acceptable and potentially effective in giving parents strategies for managing their day-to-day stress; however the long-term impact of the intervention was not measured and it is therefore not possible to generalise these findings. The small sample size of this study and negligible male participation further limits the intervention's acceptability in terms of being generalizable specially to fathers or other male members in the family caring for a child with a developmental disability.

Overall, this thesis has added to the existing evidence in the field and offered insights into the stress and coping behaviours of parents caring for children with developmental disabilities. It provides encouraging evidence that brief self-help coping interventions may help some parents manage their stress. These initial findings now need to be explored through a larger controlled trial where the longer-term impact of the intervention and identification of sub-groups of individuals who may be more or less likely to benefit from such an intervention can be explored.

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CHAPTER 1

Introduction

The introductory chapter of this thesis provides an overview of the following thesis. The chapter commences by outlining the specific focus of the thesis and providing a definition of the term developmental disability. This chapter then provides an overview of the prevalence of stress in parents of children with developmental disabilities. Henceforth; it describes the role of coping, its variability and its relationship to the development of the coping intervention. The chapter concludes with the brief aims and findings of each of the three studies conducted as a part of this PhD.

According to the Centre for Disease Control and Prevention (CDC, 2015), developmental disabilities have been defined as a group of chronic conditions which are a result of an impairment in either or all areas of physical, language, behaviour or learning abilities, with an onset during the developmental period and usually lasting throughout a lifetime. The term developmental disability will be referred to as an umbrella term for chronic conditions in children from birth to adolescence throughout the thesis. The most common causes for developmental disabilities include genetic or chromosomal abnormalities, infections before or just after birth, premature birth, poor nutrition, certain viral infections during pregnancy, prenatal exposure to substances amongst a host of others (Leslie Rubin & Crocker, 1989; National Library of Medicine, 2017). Examples of developmental disabilities include conditions such as Autism, Down Syndrome, Foetal Alcohol Syndrome, Spina Bifida, Cerebral Palsy, Attention Deficit

Hyperactivity Disorder, Hearing and Speech impairments, Muscular Dystrophy, Intellectual Disability, Prader Willi Syndrome amongst a host of others (National Library of Medicine, 2017). Statistics from the disability prevalence estimates reveal that in the UK, there are 0.9 million children with developmental disabilities under the age of 18 (Gov.UK, 2014). Figures also reveal that almost 99.1 per cent of disabled children are cared for at home by a parent or another family member (Contact a Family, 2011).

With so many children with disabilities being cared for at home, it is cognizant to bear in mind the significance of the invaluable role that the parents play in their child's upbringing. Research has identified the eminence of this multi-dimensional and multi-faceted role alongside the magnitude of the parents' contribution and duty towards providing care to their child (Hodgetts, Nicholas, Zwaigenbaum, & McConnell, 2013; Resch, Benz, & Elliott, 2012 Scorgie & Sobsey, 2000; Seligman, & Darling, 2017).

Caring for a child with a developmental disability can have a multitude of implications for the parents (Green, 2007; Hall et al., 2012; Hastings, Allen, McDermott, & Still, 2002; Hastings, Beck, & Hill, 2005; Hayes, & Watson, 2013;). For example, the very moment when a child is diagnosed with a developmental disability increases a parents' vulnerability to stress due to various factors such as, the probable permanency of the unwelcome situation (Glidden et al., 2006), the unexpected unfolding of events, health (Grosse et al., 2009) and social concern amongst others (Smith et al., 2009). Beyond this stress of the initial diagnosis, a number of factors such as escalated caregiving demands (Crnic & Law, 2002); difficult dealings with professionals involved with their child (Blacher & Hatton, 2007) additional financial strain (Parish et al., 2004) lack of social support and inclusiveness (Suarez & Baker,

1997) contribute to the problems faced by parents of children with disabilities. It is clear, therefore, that parenting a disabled child goes beyond 'ordinary' parenting and it is not surprising, that parents of disabled children are more likely to experience a multitude of difficulties in all walks of life (Davis & Carter,2008; Egan & Walsh, 2001; Hassall, Rose, & McDonald, 2005; Rao & Beidel, 2009).

Empirical research suggests that parents of children with developmental disabilities bear more stress over extensive periods in comparison to parents looking after typically developing children (e.g. Glidden & Schoolcraft, 2003; Hauser-Cram et al.,2013; Herring et al., 2006; Keller & Honig, 2004; Lee, 2013; Neece, Shulamite, & Baker, 2012; Raina et al., 2005). In the case of raising a child with disabilities, parenting demands are often complicated by factors associated with the child's diagnosis, for example, providing long term care based on the child's capacity (Cushner-Weinstein et al., 2008; Glidden et al., 2009; Lach et al.,2009) or additional emotional, communication, motor or behavioural needs; increasing the dependence of care requiring constant and consistent supervision which may lead to higher levels of parenting burden and stress (Beck, Daley,Hastings, & Stevenson, 2004; Grosse et al., 2009; Knussen & Sloper, 1992), and can potentially compromise their ability to parent effectively (Johnston et al., 2003). Physically and mentally demanding caregiving tasks related to additional parenting duties often result in exhaustion and higher levels of stress in families of children with disabilities (Olsson & Hwang, 2002).

Despite most studies in disability literature focussing and highlighting on parental stress demonstrate the implications of the high levels of stress associated with parenting a child with a developmental disability, researchers now argue that many families demonstrate remarkable resilience and a positive focus towards the disability (Beighton, & Wills, 2017; Folkman & Moskowitz, 2000; Green, 2007; McConnell, &

Savage, 2015). Parents also report positive and negative aspects of caring for a child with a disability as independent of each other (Hastings et al., 2002, 2005; Myers, Mackintosh, & Goin-Kochel, 2009) demonstrating their ability to adapt to the situation. However, it can be contended that depending upon the nature and severity of the child's disability the stress levels remain heightened. For example, a family with an adolescent child with a complex physical disability may be under a lot of physical strain in helping the child with moving, toileting, sitting etc. This may cause both physical and mental exhaustion leading to stress, despite having a positive outlook towards the overall situation. As the role of a parent changes into that of a carer, an inevitable role change occurs and causes stress because of its ubiquity over the life course and its consequences (Arigo & Smyth, 2012).

However, the differences in the experience of stress can vary from parent to parent based on a host of variables such as personality factors, sense of coherence and individual differences to name a few (Olsson & Hwang, 2001; 2002; Slattery, McMahon, & Gallagher, 2017; Willis et al., 2016). Thus, parenting stress can manifest itself in varying degrees and magnitude depending on the individual exposed to it. It can be exacerbated with time due to the continual nature of the stressor and if not managed properly may lead to unmanageable stress in the parent causing a disruption in their caring role.

There is accumulated evidence that suggests that stress can affect an individual's health by impacting on autonomic and neuroendocrine responses and by changing health behaviours. This heightened stress can have implications in terms of the parents' physical, psychological and mental well-being and the child's care eventually. However, despite these potential implications on the parents' health and the child's care there have been scant attempts to develop appropriate coping interventions designed for parents of children with developmental disabilities to minimise stress and promote effective coping techniques.

According to McCann et al., (2012) for parents of children with a developmental disability, the burden of care giving does not decrease proportionately as the age of the child increases. This makes parenting a rather exhaustive and stressful process, considering such implications it is important for parents to be able to mediate their levels of stress by using effective coping strategies. Psychological models of stress and coping such as the transactional model of stress and coping (Lazarus & Folkman, 1984) provide potentially important frameworks for understanding these processes. According to this model, stress is a mutual relationship between the person and circumstances of the environment that are appraised by the individual as challenging. Further explaining this model Lazarus & Folkman, (1984) explain that coping is (i) process oriented rather than trait based, and (ii) it should not be likened with psychosocial outcomes as it focuses on the *attempts and efforts* to master a given situation. . The goal of coping is to strengthen or maintain family resources, protect the family from the demands of stressful encounters (Judge, 1998), reduce the sources of stress or negative emotions (McCubbin, 1979), and achieve a balance in family functioning (McCubbin et al., 1980). According to Schilling, Gilchrist and Schinke (1984) personal coping mechanisms are a vital resource in dealing with the inordinate demands of caring for a child with a di1sability and parents gain increased personal coping skills when they are in a caring role most of their time. However, the coping strategies that parents use to manage this stress may differ from one parent to another based on a wide variety of factors influencing their ability to cope. Factors such as their interpretation and appraisal of the crisis event (Lazarus, 1991; Lazarus & Folkman, 1984) their personality, situational factors and the family's sources of support, resources, and family structure (Bailey & Smith, 2000; McCubbin & Patterson, 1983) may all have an influence on how they cope with a particular stressful situation.

There have been several different models and hypotheses about the structure of coping (e.g. Endler & Parker, 1990; Lazarus & Folkman, 1984; Miller, 1994; Scheir et al., 1986; Skinner, Edge & Sherwood, 2003). According to the transactional model, (Lazarus & Folkman, 1984) in the broadest sense, the process of coping serves two functions: one of which is to manage the stressful situation i.e. problem-focused coping, and the other being regulating the emotions caused by the stressful situation i.e. emotion-focused coping (Folkman & Moskowitz, 2004). Problem-focused coping is future-oriented and focused on problem elimination, whereas emotion-focused coping places emphasis on the present through eliminating negative feelings related to the stress experienced. However, evidence suggests that this division of coping oversimplifies how people deal with adversity (Carver, Schneier, & Weintraub, 1989; Lazarus, 1996; Skinner, Edge, Altman, & Sherwood, 2003). The type of coping strategies used by an individual have a strong impact on the amount of stress experienced and depending upon which type of strategy is used; one form of coping can be more effective than another (Bailey & Smith, 2000; Lazarus & Folkman, 1984).

A somewhat different classification of coping has been proposed by Skinner et al., (2003) which categorises coping in a hierarchical model. The authors argue that due to the nature of coping it cannot be unequivocally observed and that all coping responses are calibrated to specific demands and are influenced by the resources and contexts in which they unfold, and therefore may virtually be infinite in their variety. Flexibility in coping hence can foster better psychological adjustment to stressful life events by encouraging adaptability to deal effectively with a stressful encounter (Benson, 2010; Mischel & Shoda, 2000).

According to Lazarus and Folkman (1984) the choice of coping responses is dependent upon the perception of the appraisal of the situation as either changeable or unchangeable and the selection of appropriate coping measures ideal for the specific context. The 'coping effectiveness theory' transcends this approach and conceptualises 'adaptive coping' to occur when coping is further characterised by an effective 'fit' of strategies (problem and emotion) dependent upon the variability or changeability of the stressful situation (Chesney, Chambers, Taylor, Johnson & Folkman, 2003). Several studies indicate that 'adaptive coping' can decrease psychological distress if there is 'a goodness of fit' between a chosen coping strategy and the changeability of the situation (Chesney et al., 2003; Forsythe & Compass, 1987). This type of coping can occur if the coping response is based upon cognitive appraisal, with strategies that have been ineffective in the past being relinquished and new coping mechanisms having the potential to deal with the stressor are employed and constantly evaluated for effectiveness.

In the case of caring for a child with a developmental disability, some stressors the parents may face could be changeable (such as the child's behaviour problems) whereas some might be potentially unchangeable (such as the child's diagnosis). Hence, it is hoped that parents make use of effective coping strategies frequently depending upon the situation they are in. So that the adaptive qualities of the coping efforts can be harnessed and coping may serve both instrumental and affective functions. Therefore, it is important that parents caring for a child with a disability are able to identify and vary their coping strategies depending upon the specific context of the situation in order to reduce levels of stress. Acknowledging these considerations, an intervention (a self-help coping leaflet) was designed to minimise stress and promote well-being in parents caring for children with developmental disabilities. This intervention as based on its components, function and outcomes was classified as a complex intervention and the steps outlined in the MRC framework (2000; 2008) for developing complex interventions were adhered to. According to this framework, the process of the development and evaluation of complex interventions has several distinct phases, this phased approach was followed to guide this thesis as it set out the objectives to be met at each stage prior to moving forward to the next stage. The phases in this framework are (1) 'Pre-Clinical' or theoretical (2) Phase I or modelling (3) Phase II or exploratory trial (4) Phase III or main trial (5) Phase IV or long term surveillance. Phases from pre-clinical to Phase II were followed for the adaptation of the self-help coping leaflet for this thesis. The techniques included in this intervention were psychological in nature and designed in a way such that they could be delivered through a simple written self-help coping leaflet. The leaflet included information on a range of standard cognitive behavioural coping skills, along with a choice of coping strategies and their application (King & Kennedy, 1999). It was hoped that the coping leaflet may prove to be an effective and appropriate intervention for parents helping to reduce their levels of stress and enhance their well-being.

Aims of the Thesis

The aim of this thesis was to examine the process of stress and coping in parents of children with developmental disabilities and to develop a brief coping intervention which may help these parents to cope with their day to day stress. In order to meet this aim, the PhD consisted of three unique but interlinked objectives, these were:

1. To understand how parents perceive their role as a primary giver to a child with a developmental disability and their perception of stress and efficacy in coping associated with this role.
2. To develop and assess the acceptability of a self-help coping intervention developed to promote the effective use of coping strategies, which aim to provide opportunities to reduce stress in parents of children with developmental disabilities.
3. To evaluate the impact of the usage of the self-help coping leaflet on the parents' stress and coping behaviours.

Three studies, each with a distinct set of analysis were conducted in order to meet the objectives of this study. The overall research follows a pragmatic paradigm comprising of both qualitative and quantitative research methods where the broad approach used was phenomenological and the applied approach was structured around the intervention development framework as outlined by the Medical Research Council (MRC, 2000). Study One was a qualitative study analysing the subjective experience of stress and coping in parents of children diagnosed with developmental disabilities and followed the Pre-clinical phase of intervention development, to explore relevant theory to ensure the choice of the intervention and identify its components (MRC, 2000). Studies Two (Phase I) and Three (Phase II) were exploratory in nature, aiming to evaluate the intervention in order to obtain evidence to identify appropriate outcome measures, estimates for recruitment and to support the theoretically expected effect of the intervention as outlined by the Medical Research Council guidelines for developing complex interventions (MRC, 2000).

Study One: A Qualitative Interview Study

A qualitative interview study was conducted with the aim of gaining an understanding into a parents' experience of raising a child with a developmental disability. The study aimed identify:

1. The key challenges and stressors as identified by the parents in their role as a primary care giver for the child.
2. The range of coping strategies used to overcome or minimise parenting stress.

The results of this qualitative study revealed a prevalence of high stress amongst parents of children with developmental disabilities. The participants perceived their role as a primary caregiver as very stressful and demanding often leading to exhaustion and affecting them both mentally and physically. However, the participants also acknowledged the benefits and positive emotions they experienced as a result of their care giving role. The analysis indicated that the participants used a varied array of coping styles and certain preferential coping strategies to deal with their stress. This information was used as a guide to adapt and develop the coping intervention in the second study.

Study Two: The Development and Piloting of the Self-Help Coping Intervention

A pilot study (corresponding to an MRC Phase I trial) using qualitative interviews was conducted to assess the acceptability and feasibility of the intervention i.e. the self-help coping leaflet. The key aims of this study were to:

1. Assess the acceptability and relevance of the self-help coping intervention.
2. To explore the preferences, appeal and ease of usage of specific coping interventions.

The results of the literature reviewed in this chapter reinforced the need for the development of an intervention for parents of children with developmental disabilities. The analysis of the data gathered from the participants suggested that the coping leaflet may be an effective tool in minimising levels of distress and enhancing coping effectiveness amongst parents. The participants also shared their views on how to further improve the existing coping leaflet, based on these suggestions a few changes were made to the final version of the self-help coping leaflet.

Study Three: The Evaluation of the Effectiveness of the Self-Help Coping Intervention

An exploratory longitudinal trial was conducted (corresponding to an MRC Phase II trial) to explore the effectiveness of the self-help coping intervention. The main aims of this study were

1. To explore whether the use of the intervention will result in lower levels of perceived distress and parental stress over time.

2. To compare the impact of the intervention on coping strategies.

The results of this study revealed that there was a significant change in levels of stress in participants at the pre-intervention and post-intervention stages, leading to the conclusion that the intervention had a desirable effect of reducing stress on the users. The results also revealed that there is a strong association between coping styles, parental distress and perceived stress.

Structure of the Thesis

The following thesis will review the literature from the fields of psychological stress, the coping theory in relation to childhood disability and parenting stress. Methodological and ethical considerations will be reviewed following theoretical underpinnings of this research. The studies outlined above will be detailed in sequence in their own independent chapter, with their specific results and relevant discussion. The thesis will then continue with a general discussion amalgamating the findings of the three studies and discussing them in relevance to each other and to the existing literature. The relevance and contribution of the intervention and how this intervention may inform the development of future interventions aimed at reducing stress in parents of children with developmental disabilities will also be discussed in light of the findings of this study.

CHAPTER 2

Stress and coping in parents of children with developmental disabilities: empirical literature review

The aim of this chapter is to provide a critical review of the psychological evidence underpinning this thesis. The review of literature begins with an introduction to the term developmental disabilities, and includes definitions, manifestations and data on prevalence of such conditions. This is followed by a critical review of the literature reporting the experience of being a parent of a child with a developmental disability and the psychosocial challenges which these parents face as a part of their caring role. The impact of the child's disability on the parents' well-being is discussed with emphasis on the implications of their care-giving role on their physical and mental well-being, finances and their social and personal relationships. This is followed by a discussion of the growing recognition of the role of positive emotions in coping and adaptation amongst parents. The final section of this chapter provides a review of psychological intervention studies in the childhood disability literature, leading to the rationale for the development of the intervention within this thesis.

Developmental Disabilities: Definition and Types

According to the Centre for Disease Control and Prevention (CDC, 2015), developmental disabilities can be defined as a group of conditions caused by an impairment in physical, learning, language, and/or behaviour areas. These disabilities may begin anytime during the developmental period and usually last throughout a person's lifetime (CDC, 2013). Most developmental disabilities are initiated before a baby is born, but some may also occur after birth because of injury, infection, or other environmental factors (Boyle et al., 2011). According to the Office on Women's Health (2010), an increased risk for many developmental disabilities can be associated with a complex mix of factors such as the genetic makeup, parental health, complications during pregnancy and child birth such as low birth weight, premature birth, multiple birth, and infections during pregnancy. Environmental factors such as exposure to smoke or toxins may also be reasons for a developmental disability (CDC, 2015). Common known causes of intellectual disability include foetal alcohol syndrome; genetic and chromosomal conditions, such as Down syndrome and fragile X syndrome (King, 2008). Some conditions such as new-born jaundice if left untreated makes babies more prone to brain damage increasing the likelihood of these children having cerebral palsy as well as hearing and vision problems (Chung et al., 2004; Juul-Dam,,Townsend, & Courchesne,2001). A developmental disability can either be severe, moderate, or mild, depending on an individual's support needs and may appear among all racial, ethnic, and socioeconomic groups (Roeleveld, & Zielhuis, 1997).

According to the National Dissemination Centre for Children with Disabilities based in the USA (NICHCY,2011), developmental disabilities can be divided into four main types based on their origin. These are nervous system disabilities, sensory related disabilities, metabolic disabilities and degenerative disorders. These are outlined below and a myriad of different subsets of disabilities may abide under these four main groups.

Nervous system disabilities: Nervous system disorders / disabilities are birth defects that can potentially affect the normal functioning of the brain, spinal cord and the central nervous system. This may result in behavioural and movement disorders, speech and language complications, movement disorders and convulsions. Common nervous system disabilities include, but are not limited to Intellectual disability, Down syndrome, Fragile X syndrome, Autism Spectrum Disorder (Centres for Disease Control and Prevention, 2012).

Sensory related disabilities: Sensory related disabilities are defects that interfere with the normal function of a body's ability to sense the world around it. Children with this condition have difficulty in using and processing sensory information including tactile, auditory, visual, gustatory, olfactory, proprioceptive, and vestibular systems (Bundy &

Murray, 2002). These disabilities are often a part of complex birth defect patterns, for example, children diagnosed with William's syndrome have difficulty seeing and perceiving depth; and spatial relationships between objects around them. Sensory related disabilities can also be found in those with autism, ADHD, Asperger Syndrome, Learning disabilities and OCD amongst a host of others.

Metabolic disabilities: The National Institute of Child Health and Human Development (2016), outlines that these disorders interfere with an individual's metabolism, which is the way of the body building up, breaking down and processing materials it needs to function. An example of a common metabolic disorder is Phenylketonuria, a condition where the body can't break down the amino acid phenylalanine resulting in its build up in the blood and brain leading to brain damage, seizures, behavioural problems and mental disorders.

Degenerative Disabilities: The neurodegenerative diseases of infancy and childhood include disorders in which there is progressive loss of neurological function due to structural abnormalities of the central nervous system (Dyken & Krawiecki, 1983). Infants born with these disorders may appear normal at birth, but gradually lose abilities or functions as a result of this condition. Depending upon the specific defect degenerative disorders can result in sensory, mental and physical problems. A common example of a degenerative birth defect is Rett Syndrome which is present from conception but remains undetected initially. This condition affects more females in comparison to males and results in profound physical and communication disabilities (Genetics Home Reference, 2013).

The causes, types, extent and implications of developmental disabilities are varied and can affect the lives of the children diagnosed and their parents likewise. The following section highlights the prevalence of developmental disabilities within the United Kingdom.

Prevalence: Recent estimates in the United Kingdom indicate that 0.9 million children have one or more disabilities (Department of Work and Pensions, 2014).

Neurodevelopmental conditions, ADHD, impairments affecting speech, language and communication, and learning difficulties are the most commonly reported primary disorders or diagnoses (Annual Report of the Chief Medical Officer, 2012). Functional impairments in children with developmental disabilities are varied and can comprise of either, some or all impairments relating to mobility, physical coordination, manual dexterity, continence, communication, memory, learning and perception of threat (Annual Report of the Chief Medical Officer, 2012. Our Children Deserve Better: Prevention Pays). Children with these conditions, experience a number of impairments and co-morbidities which may result in complex medical, educational and social support needs.

The psychosocial impact of caring for a child with a developmental disability:

According to Crown (2009), following a diagnosis of a developmental disability in their child, parents can be temporarily deprived of their hope and the ordinary parental pride. In general, parenthood is a profoundly challenging and transformative experience, additionally, realising that their child has a disability can be disorganising, fragmentising and ravaging for a parent (Baxter, Cummins & Polak, 1995; Crown, 2009; Trad, 1990). With the birth and diagnosis of the child with a developmental disability emerges a struggle within the parent to negotiate the difference between the actual child (i.e. with the developmental disability) and the ideal child of the parents' fantasies (Bowlby 1980, Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009). Citing Condon and Dunn (1988); Trad (1990) writes, "…parents who have invested considerable energy in the representation of a fantasy baby, who personifies the ideal child, may face, in the presence of the neonate, the loss of that imagined and already loved child" (p. 355). The diagnosis can be therefore be the start of a life-long journey of struggle, learning and adaptation for the parents.

Families of children with developmental disabilities tend to be less satisfied with their quality of life in comparison to families of typically developing children (Gardiner & Iarocci, 2012; Mugno, Ruta, D'Arrigo & Mazzone, 2007). It is well documented in literature that parents of children with disabilities report higher levels of parental stress in comparison to families of typically developing children (e.g. Britner et al., 2003; Dabrowska & Pisula, 2010; Dykens, Fisher, Taylor, Lambert & Miodrag, 2015; Grosse et al., 2009; Hastings and Johnson, 2000; Hayes, Watson, 2013; Knapp, 2005; Neece, Green, & Baker, 2012; Smith, Oliver & Innocenti, 2001; Sivberg,2002; Spratt et al., 2007; Weiss 2002). Parents caring for children with developmental disabilities face some rather unique and difficult parenting tasks along with more intricate caring duties. This may result in an increased risk for excessive levels of psychosocial stress, which in turn can adversely affect the well-being of the child and the family as a whole (Resch et al., 2010; Resch, Elliott, & Benz, 2012).

Research carried by a charity working to support families of children with disabilities, Contact a Family (2013) revealed that 99.1% of disabled children live at home and are supported by their families, and only one in 13 disabled children receive a regular support service of any sort from their Local Authority. These findings are indicative of the high numbers of children with developmental disabilities being cared for by their families. These families face the incessant effects of their caring responsibilities which can have life changing implications on parents as they meet these exceedingly rigorous and challenging demands (Resch et al., 2010; Resch, Benz, & Elliott, 2012). According to Murphy, Christian, Caplin & Young (2006) this informal duty of care giving and the responsibility for long-term care for their child is often associated with the use of extraordinary physical, mental, emotional, social and financial resources. As a result of playing such a pivotal role in the child’s well-being, parents can face significant challenges, consequently, making them susceptible to an increased risk of personal distress which in turn can adversely affect the well-being of the child and the entire family unit (Abbeduto, 2004; Bailey, Golden, Roberts, & Ford, 2007; Hallberg, 2014; Plant & Sanders, 2007). The following section discusses the main factors associated with increased stress and poorer wellbeing in parents caring for children with developmental disabilities.

For parents the diagnosis of certain disabilities such as Spina Bifida, Missing or undeveloped limbs, Sickle-cell disease, Down syndrome which can be detected soon after birth (CDC, 2014) make it an immediate and sudden event if not detected in prenatal screening. Whereas for other disabilities which may be diagnosed after some time or years such as developmental delay, autism, Williams syndrome, the years preceding the diagnosis may be highlighted with the child’s distinctive needs or behaviours but the parents may have no concrete sense of anything potentially amiss till they receive a diagnosis. For some disabilities the diagnosis may cause a profound shock or dismay (Seligman & Darling, 2007); whereas, for other disabilities such as autism or developmental delay the diagnosis maybe a confirmation of an unformulated sense in the parent that something is “not quite right,” a feeling that is a result of a tentative sense when their child fails to meet particular developmental milestones or through comparison to other same-age children (e.g. Gensler, 2009). The diagnosis may result in a sense of loss to the parents as the image of their child is transformed with the confirmation of the diagnosis (Crown, 2009). In many cases, the parents may self-blame for their child’s condition, such as culpability in their faulty genes (Featherstone, 1980). Hereafter, as the reality of the diagnosis sinks in, concerns for the child's well-being overshadow the ambiguity and the parents turn toward evaluation of their situation and the diagnosis (Gensler, 2009).

Depending upon the nature of the diagnosis, there might be various functional limitations in the child with a developmental disability such as a significant lack of social skills, language and self-care amongst others, resulting in deficits, which demand ongoing care (Carpenter, 2002; Lach et al., 2009; Minnes, Perry, & Weiss, 2015). Such complex care needs of children with developmental disabilities are strongly associated with high levels of stress experienced by their parents (Grosse et al., 2009), as they are the main unit responsible for the child throughout their childhood, adulthood and beyond (Carpenter, 2002). These parents face greater challenges associated with the uneven developmental progress of their child (Gray & Holden, 1992; Rivard, Terroux, Parent-Boursier, & Mercier, 2014; Schuntermann, 2002), excessive care taking demands, increased financial burden and social isolation making them more prone to developing psychological difficulties and to higher levels of parenting stress (Fidler, Hodapp, & Dykens, 2000; Miodrag, Burke, Tanner‐ Smith, & Hodapp, 2015; Sharpley & Bitsika1999). These high levels of parenting stress have been consistently linked to the extent of problem behaviours in children including aggression, hyperirritability, self-injurious behaviours, noncompliance, being easily distressed, lower levels of social relatedness (Davis & Carter, 2008) and poor communication skills (Hassall, Rose & McDonald, 2005; Tomanik, Harris & Hawkins, 2004).

Baker et al., (2003) concluded that a transactional relationship existed between parenting stress and behaviour problems: high parenting stress contributed to a worsening in child behaviour problems over time, and high child behaviour problems contributed to a worsening in parenting stress, suggesting a positive correlation between parenting stress and child behaviour problems in children with developmental disabilities. The relationship between child characteristics and parenting stress over time in this study were examined using two sets of hierarchical multiple regressions, the results of this analysis revealed that child behaviour problems predict subsequent mother and father stress levels, after accounting for prior stress (Baker, 2003). Moreover, parental stress predicted subsequent child behaviour problem levels, after accounting for prior behaviour problems, however, it is hard to generalize the findings of this study because the sample consisted of parents with children aged three years and the findings may only be relevant to this age group. Future studies examining this phenomenon may benefit greatly if the study population is varied in terms of the child's age and diagnosis so this link may be reaffirmed.

However, an important argument in establishing a link between the diagnosis and parental stress is that with the passage of time the parents may get more confident about their child’s diagnosis. They become better equipped to deal with subsequent problem behaviour and treatment routines; hence, gaining some mastery over the day to day care routine and behaviour of the child, thereby making them more resilient to this stress over time. Some parents hence may be able to cope better than the others by diminishing or minimising the perception of the child’s problem behaviour with time. Parents may sometimes adapt to their life situation and cope by accepting the reality and subtleties of their child’s diagnosis, resulting in a less stressful life situation. Macias, Roberts, Saylor, & Fussell, (2006), demonstrate this in their study, which examined the relationship between toileting concerns, behaviour problems, and stress in parents of children with special health care needs. The participants in their study included parents of 99 males and 71 females aged 4 to 12 years with neural tube defects (NTD), developmental-behavioural disabilities (DBD), or history of perinatal intraventricular haemorrhage (IVH). The measures used were the Achenbach Child Behaviour Checklist (CBCL) used to measure child behaviour problems in children 4 to 18 years old and the Parenting Stress Index–Short Form (PSI-SF). Findings revealed that parents expressing toileting concerns on the CBCL reported significantly more personal distress and more externalizing problems versus those with continent children. The results of this study also revealed that when problems with toileting are expected due to the nature of the disability, parents experience less stress related to toileting concerns than when the child physically appears “normal.” Therefore, the parents may adapt their expectations of life events and utilize coping strategies to accept concerns (for example, toileting issues, issues with speech, hearing or mobility, learning) as a symptom of their child’s disability as a result lowering their stress appraisal (Hassink et al., 1998). Hence, parents need to initiate relevant coping mechanisms and continually appraise the stressors in light of the nature of their child’s diagnosis/ condition.

Whilst researching the link between parental stress and behaviour problems of children with developmental disorders Hastings (2002) concluded that parental stress is elevated if a child displays behaviour problems irrespective of the level of intellectual abilities. In a similar research study, Tomanik, Harris & Hawkins (2004), warranted that mothers of children with autism reported the greatest stress when their children were more irritable, socially withdrawn, hyperactive, non-compliant, unable to take care of themselves, and unable to communicate or interact with others. Unlike many studies of this kind, the authors specifically measured child adaptive behaviour with the aim to assess the impact of such behaviour on maternal stress levels. The results indicated that child adaptive behaviour levels were significantly related to maternal stress as measured by the parental distress subscale of the PSI (Parenting Stress Index, Abidin, 1995). However, it can be argued that in studies establishing the link between child behaviour and parental distress, the intellectual functioning of children needs to be assessed in order to determine whether or not the findings are specific to parents of children with a particular type of disability or if they can be generalized to all developmental disabilities.

Impact of care-giving duties

Given the complex nature of these disabilities, the care duties performed by parents are unsurprisingly associated with significant and prolonged periods of time and energy being spent on physically demanding and unpleasant tasks, and persistent disruption to routines and activities of the family (McDonald, Couchonnal, & Early, 1996; Seltzer & Heller 1997; Shultz & Quittner 1998; Weiss, 2002). According to Todd & Shearn, 2000; and Weiss, 2002; the nature and range of care duties such as feeding, washing and supervising children with developmental disabilities also segregate mothers from their peers as these tasks involve much more participation and time, making caring very demanding in comparison to mothers of non-disabled children.

As a result of the high caring demands parents may feel overwhelmed by the stress of the incessant role they play in their childs' life which may have underlying negative implications for the child, the parent and the family as a whole (Bor et al. 2002). Therefore, it is important that this stress is recognised and parents given an opportunity to exercise their coping mechanisms with the aim to address their particular stressor. Plants and Sanders (2007) conducted a study to examine the predictors, mediators and moderators of parent stress in families of children with developmental disabilities. One hundred and five mothers of preschool-aged children with a developmental disability completed assessment measures addressing the key variables of most stressful caregiving tasks that parents undertake in their daily routine, the stressfulness of these tasks, their difficulty; the time involved in completing these tasks and the assessment of the frequency of difficult child behaviour when completing care-giving tasks. Other measures included the severity of the child’s disability, the parents’ appraisal of the care-giving role, social support and the use of coping strategies. The results of the analysis revealed that the difficulty parents experienced in completing specific care- giving tasks, behaviour problems, and level of child disability, respectively, were significant predictors of parent stress. However, findings of this study may be limited in their generalizability to other samples. Participation was voluntary and based on self-referrals in this study and the demographic information indicated that the sample consisted of predominantly two-parent families where parents had relatively high educational level and socio-economic status. In addition, mean age of parents was over 35 years. Thus, it cannot be assumed that results would be similar if the sample consisted of younger parents or one-parent families with lower educational and socio-economic backgrounds. There was a small percentage of fathers who participated in this study (n=43) and an analysis of the fathers data was not conducted thereby limiting the findings to only mothers.

It is clear that the parents are the main unit responsible for the physical care of their child, and for their child’s numerous and multifaceted medical, educational and developmental interventions while adjusting other competing family needs to retain an equilibrium with the family (Silver, Westbrook & Stein,1998). This pressure of balancing their lives around their child's needs clearly has an impact on their own well-being. Murphy, Christian, Caplin and Young (2006), conducted a qualitative study with four focus groups with the aim to explore the issue of caregiver health by focusing on the caregivers own perspectives. The authors found that caregivers who provided most or all of the direct, daily care for their children with disabilities reported poorer health than those who provided little or no care. Forty-one per cent of the caregivers in this study reported that their health had worsened and attributed these changes to a lack of time, a lack of control and decreased psychosocial energy due to their incessant caring responsibilities. With the aim of assessing the time commitment required to care of children with disabilities 133 mothers were asked to estimate the extra time required by parents for specific caring duties for their child. Results revealed that the average care time daily was equivalent to 12 hours and 6 minutes, out of which six hours and 30 minutes were vigilant (i.e. watching a child who cannot be left alone or comforting the child). These results are an indication of how this time of care taking is a cause for lost opportunities for parents. These lost opportunities due to care taking are implicated further by the costs involved in caring for a child with developmental disabilities. These factors when put together reveal the true nature of caring and its implications.

In a study to understand the cost implications of parental burden of caring for a child with ASD; Jarbrink, Fombonne and Knapp (2003), collected parental information about time spent on informal care via a pilot instrument of questionnaires and diaries. Parents reported that, on average, they spent nearly 60 hours a week caring and supporting their child due to the disorder and estimated that they lost 40 hours a week that they would have spent on other activities. The time pressure these parents face reduces the time available for other activities, including but not limited to work, leisure and personal care (Brandon, 2007; Carnevale et al., 2008). In the case where parents are working they may often rely on family or parental leave to meet the health needs of their child (Green, 2007).

McCann, Bull and Winzenberg (2012) conducted a systematic review to gain a better understanding of the time expenditure of parents of children with disabilities and how this compares to the parenting experience of typically developing children. They reviewed a total of 32 studies which met their inclusion criteria and concluded that, parents of children with complex needs carry a significant caregiving burden that often does not reduce with the child's increasing chronological age (Bourke-Taylor et al., 2010). For example, physical care which usually includes hygiene, dressing and toileting, with the possible addition of feeding is a significant daily time requirement for parents of children with complex needs. Also, the number of items of personal care that children with complex needs require per waking hour does not decrease with increasing age, in contrast to the negative correlation between increasing age and frequency of personal care items for typically developing children (Curran et al., 2001). Studies included in this review also indicated that significant time may be spent feeding children, particularly when the child has severe impairments that impact on their ability to eat. For example, parents of children with spastic tetraplegia spend an average of 113 minutes/day feeding their child (Edebol-Tysk, 1989). This review also identified that parents caring for children with disabilities have to devote substantial time for supervision or vigilance, for example, the review revealed that the highest parental time allocation for vigilance incorporating both watching the child and providing emotional support in some cases maybe up to 6.5 hours per day (Brust et al., 1992). The authors also reported that parents spend considerable time undertaking health care related tasks outside the ‘normal’ parenting role such as travel to appointments or treatments (may include waiting time), medication administration, education, therapy/intervention procedures and health care management. The review also indicated that parents also facilitate time within their schedules in order to attend a myriad of management responsibilities and activities including organisation and negotiation of care and accessing and coordinating resources (Sullivan-Bolyai et al., 2004). The next section of this chapter highlights how these excessive caring duties impact the well-being of these parents.

Impact of care-giving on the physical health of the parent

It has been established that the chronic stress of caregiving has an effect on several dimensions of caregiver health, including self-reported health, health symptoms, illness, and medication use (Asada, Kinoshita, & Kakuma, 2000; Glaser & Kiecolt-Glaser, 1997; Kiecolt-Glaser, Marucha, Malarkey; Schulz & Beach, 1999; Vitaliano et al., 2003; Zhang, Vitaliano, & Lin, 2006). A comprehensive review of studies aimed at finding out the link between disabilities and parental stress concluded that parenting a child with disabilities has a negative effect on the caregiver’s physical health and can consequently affect the mother’s ability to provide due care for the child and cause unnecessary disruptions in the parent child relation. The authors suggested the importance of recognising and addressing this issue to enhance the well-being of the family unit with children with developmental disabilities (Miodrag & Hodapp,2010).

As discussed earlier in this review, (page 19-20) in the case of children with developmental disabilities, it is not only the diagnosis or the condition of the child which can be a source of stress for the parents, the child's behaviour can also have a negative impact on the parent's health. The parent's health thus can be adversely affected due to their active role in managing the child's behaviour. To establish this link, Eisenhower, Baker, and Blacher (2009) conducted a correlational study with the aim to determine the impact of child behaviour problems and developmental delay on maternal physical health using a convenience sample of 218 families with a three-year-old child (126 boys and 92 girls) either with development delay (n=91) or typical development (n=127). Data for this study was primarily collected through child assessments at home, assessing the child's cognitive ability and behaviour problems at age three alongside the use of questionnaires completed by the mothers. The mother's global physical health, maternal depressive symptoms were the other measures assessed at child ages three, four, and five. The developmentally delayed child's impact on the family was compared to the impact of typically developing children his/her age (Eisenhower et al., 2009). The results of this study revealed that child behaviour problems coupled with developmental delay predicted an adverse change in maternal health. Overall, the findings of this study suggested that the association between child behaviour problems and maternal physical health were moderated by maternal stress and mediated by maternal depressive symptoms (Eisenhower et al., 2009). A sample population of both boys and girls and both delayed-developing and typically-developing children have given this study a large and diverse sample, which strengthens generalizability of the findings. However, most similar studies have assessed maternal mental health (Beck, 1999; Hastings & Brown, 2002; Olsson & Hwang, 2001) rather than maternal physical health, which limits the findings of this study in its ability to be examined against comparable studies. Other limitations of this study, which may have weakened the findings include possible maternal recall bias of symptoms of stress and depression and a lack of in-depth subjective reports (Eisenhower et al., 2009).

Prolonged stress in parents may lead to chronic conditions thereby minimising efficacy in their caring role, hence parents need to effectively address their levels of stress to continue with their caring responsibilities. In their study, Lee, Park, Matthews, and Hsieh (2017), compared the prevalence of chronic conditions and health risk behaviours of family caregivers of children with and without disabilities and examined associations between disability status of children and family caregivers' chronic conditions and health risk behaviours. Their study revealed that caregivers of children with disabilities showed significantly greater likelihood of chronic conditions such as asthma, back pain, chronic bronchitis, heart conditions, migraine, and obesity along with a higher engagement in health risk behaviours such as smoking rates and poor sleep patterns. It needs to be emphasised though, that, these results need to be considered with caution as the parents with children with disabilities in this study had a higher mean age as compared to the parents of typically developing children. This difference in age may have been a possible reason for inflated results for their chronic conditions as older age may have contributed to the higher prevalence of conditions examined in this study such as joint symptoms or hypertension. As this study was of a cross sectional nature it did not establish a causal relationship between caregiving effects and other health consequences.

Sleep quality in parents caring for a child with developmental disabilities can also adversely affect their physical and mental health. A correlational study conducted by Gallagher, Phillips, and Carroll (2010), aimed to establish if parental stress was associated with poor sleep quality in parents caring for children with developmental disabilities (Gallagher et al., 2010). Participants of the study comprised of 42 parents of typically developing children and 67 parents of children with developmental disabilities. The study involved a structured questionnaire, which aimed to assess the sleep quality of the parent, parental stress, child's problem behaviour, and social support available to the family (Gallagher et al., 2010). The findings confirmed that the sleep quality of the parents caring for a child with developmental disabilities is poorer as compared to that of parents of typically developing children. This finding is complemented by findings of related studies which determine that the strongest predictor of poor sleep quality is parental stress (e.g. Hedov et al., 2002; Hoffman et al., 2008; Lee, 2013; Meltzer, & Mindell, 2007). It can be argued however, that poor sleep quality may be a causal factor to the increased stress by reverse causation. As in most disability studies, the sample population of this study also included a higher number of females (more than 70%) than males, which decreases the generalizability of the findings to all genders.

Impact of care giving on the psychological health of the parent

Previous studies indicate that parents caring for a child with a developmental disability are at a significantly increased risk of experiencing psychological difficulties compared with parents of non-disabled children (e.g. Donenberg and Baker, 1993; Dumas et al., 1991; Fombonne et al., 2001; Hastings, 2003; Hastings & Brown, 2002; Olsson & Hwang, 2001; Sanders and Morgan, 1997; Florian & Findler, 2001). Maternal mental health is an important issue to address as it predicts the outcome for the cared for child. Literature suggests that children of depressed mothers are at an increased risk of developing behavioural health issues, as well as health complications (Harnish et al. 1995; Olfson et al. 2003; Weissman et al. 1986; 1997; 2006), and there is also a heightened potential for children of parents with depression to subsequently develop their own mood disorders (Olfson et al.; 2003). Similarly, mothers who are stressed or depressed may exhibit decreased parenting abilities (Cummings and Davies 1994; Forehand et al. 1986; Greenberg, Seltzer, Krauss, Chou, & Hong, 2004), which may negatively influence the child's physical and mental health (Harnish et al. 1995; Olfson et al. 2003; Weissman et al. 1986, 1997).

It has often been documented that the extra stress of caring for a child with disabilities places parents at risk of suffering from depression (e.g. Emmerson, 2003; Hastings 2003). Olsson & Hwang (2001), conducted a study assessing parental depression in 216 families with children with autism and/or other intellectual disabilities, and in 214 control families. Both the groups had similar demographic characteristics. The Becks Depression Inventory (1979) which has well-evaluated psychometric qualities was used to investigate the prevalence and severity of parental depression in both mothers and fathers of children with disabilities and in the control group. The results of the study supported previous research suggesting that mothers of children with disabilities are at a markedly increased risk of suffering from psychological distress and depression (e.g. Dumas et al.1991; Sanders & Morgan, 1997). The results of this study also indicated that single mothers with children with disabilities were more vulnerable to severe depression than mothers living with a partner, which supports the findings by Blacher & Lopez (1997). A relatively big sample in this study may be representative of the general population, however, there may still be a risk of psychological differences between those who completed the surveys as opposed to those who did not. As participants who were more depressed were more inclined to participate in a study like this which may also result in over reporting of symptoms. The authors of this study also noted that the results of this study relied on only a single administration of the BDI and future studies of this nature should preferably use repeated measures and structured diagnostic interviews to increase knowledge about the stability and severity of depression in parents of children with disabilities.

A qualitative study conducted by Murphy, Christian, Caplin and Young (2007), aimed to explore caregiver perspectives of the health implications of long-term informal caregiving for children with disabilities. They conducted four focus group studies with 40 caregivers of children with developmental disabilities. Amongst other findings the results of their study revealed that the caregivers' physical and mental health was adversely affected by a combination of the concrete tasks of caregiving and pervasive anxiety about their child's health and future. The study also recognised that despite the negative health impacts of caregiving, most parents in the study believed that they face significant barriers to addressing and improving their own health which may ultimately affect the outcomes for their child. In comparing studies of parents with and without children with developmental disabilities, Singer (2006), reported a small but consistent effect size difference in indicators of psychological distress in studies of mothers conducted over the past 25 years. He estimated an approximate 10% increase in the number of mothers with scores over clinical cut-off scores on standardized self-report, paper and pencil measures of depressive symptoms. Thus, roughly 30–35% of the mothers of children with developmental disabilities in these studies had elevated levels of depressive symptoms.

Impact of care-giving on social functioning of the parent

Apart from having an effect on the mental and physical well-being of the parent, caring for a child with a developmental disability can have profound effects on the parent's personal and social relationships. Playing the role of the ultimate care provider can cause either a strain in relationships or in many cases make these relationships stronger. Numerous studies propose that having a child with a disability in a family may lead to strain on the spousal relationship. Some studies have reported that families caring for a child with a disability may have a higher rate of divorce and lower marital satisfaction in comparison to families caring for typically developing children (e.g. Breslau & Davis, 1986; Bristol, Gallagher, & Schopler, 1988; Cappelli, 1990; Floyd & Zmich, 1991; Friedrich & Friedrich, 1981; Hodapp & Krasner, 1995; Kazak, 1987; Morrison & Coiro, 1999; Roesel & Lawlis, 1983; Singhi et al., 1990; Tew, Laurence, Payne, & Rawnsley, 1977; Witt, Riley, & Coiro, 2003, Wymbs et al., 2008). This vulnerability to separation between partners or divorce has been related to the high-level of parenting demands and the subsequent reduction in responsiveness to the needs of one's spouse during these years of care giving (e.g., Hartley et al., 2010; Shapiro, Gottman, & Carrere, 2000; Urbano & Hodapp, 2007).

Yet, on the other hand, there are studies which reveal that caring for a child with a developmental disability does not always have a detrimental effect on the relationship between the parenting partners or on the rates of separation, divorce and marital satisfaction (e.g. Donovan, 1988; Guess, 1998; Mullen, 1997; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Spaulding & Morgan, 1986; y. Stoneman & Gavidia-Payne, 2006; Urbano & Hodapp, 2007; Vandewater & Lansford). Risdal and Singer (2004) conducted a meta-analysis of literature to compare levels of divorce and marital satisfaction/discord in parents of children with and without developmental disabilities. They detected an overall negative impact on marital adjustment, but clarified that this impact was small and much lower than would be expected given assumptions about the supposed inevitability of damaging impacts of children with disabilities on family well-being. They also reported that in the percentage of marriages that end in divorce, there is an average increase of 5.97% (range 2.9–6.7%) among families of children with disabilities. These mixed research findings can be viewed from a resilience perspective in that many couples who have children with developmental disabilities try to maintain their emotional, cognitive, and physical equilibrium in the face of stress in order to sustain their relationships (Bonanno, 2004).

Stress in parents of children with developmental disabilities can be exacerbated by feelings of loneliness due to the limited social interactions as a result of continual care giving duties. Families of children with disabilities often report feeling isolated from the community (Egan & Walsh, 2001; Freedman & Boyer, 2000; Worcester et al., 2008). Resch et al., (2010), conducted a qualitative focus group study with the aim to identify specific sources of challenges related to raising a child with a disability as expressed by parents themselves. For the purpose data were collected from 40 parents of children with disabilities, this data was analysed using an iterative content analysis process of data reduction, data display, and conclusion drawing/verification recommended by Miles and Huberman (1994). The study identified four major themes influencing parent wellbeing as obtaining access to information and services, financial barriers to obtaining services, school and community inclusion, and family support. As in much of disability research most participants in this study were women (90%) however, this limitation should not significantly restrict the results of this study as mothers are typically the primary care providers for children with disabilities.

Another study looking at the experience of parents with children with disabilities indicated that parents, and specially mothers, experienced severe socializing problems, frequent social rejection and stigma. When this research study was followed up after nearly a decade it was found that the majority of parents still experienced social stigma and as in the previous research mothers were again more likely to experience this than fathers (Gray, 1993; 2002). However, the emotional impact of stigmatization declined over the years, as a number of parents in this longitudinal study noted its continuing occurrence, but claimed that it mattered less to them in comparison to the previous years. The reasons for this change could likely be improved public behaviour over the years by the child, deliberate restrictions in the families' social lives and a decreased sensitivity towards the reactions of other people towards their situation.

Similarly, with the aim of understanding the experiences of parents who have children with autism, Woodgate, Ateah and Secco (2008), conducted a hermeneutic phenomenological study which revealed that social isolation is a cause of major concern amongst this group. Parents in their study acknowledged that they suffered from a feeling of isolation because of what they perceived as a lack of understanding by society of what autism is and what is involved in caring for a child with autism. The parents felt that their suffering was not recognized by others around them but instead was invisible despite the challenging nature of their child's diagnosis. Due to the intensive care their child required, parents' in this study reported feeling disconnected from their family and friends who seemed to lack an essential understanding of what they were going through and failed to be present to provide much needed practical support and assistance. For participants in this study isolation became the essence of their overall experience, in contrast to a similar study where Gray (1993, 2002), reported isolation in the parents was more self-imposed as parents tended to isolate themselves from social contact with the outside world because of the stigmatization and awkward encounters with outsiders.

This feeling of isolation in parents may not just be in terms of the society they are living in but also in the institutions they are dealing with. Isolation may be further compounded with the difficulty in accessing resources and information related to the care and upbringing of their child. Various studies acknowledge that in the case of disabilities finding relevant information and resources to meet their child's needs is an ongoing process which is often complicated by a system of services which is complex, uncoordinated, and that is perceived too often as unhelpful (Redmond & Richardson 2003; Stebnicki, & Marini, 2012). Studies have found that gaining accurate and useful information is a major stressor encountered by parents of children with developmental disabilities (Freedman & Boyer, 2000; Worcester et al., 2008). Parents often report that they feel unprepared for their encounters with the professionals and are unable to fully comprehend and clarify the information provided to them. They also feel that they are given a very limited opportunity to offer their own perspectives on their child and have their perspectives honoured and validated by professionals (Pentyliuk, 2002, Ryan, 2005; Seligman & Darling 2007). Several studies have consistently noted considerable difficulties in the relationships between parents and professionals, and often these relationships are more negative than positive despite good intentions (e.g., Kroth, 1987; Turnbull, 1983, Waggoner & Wilgosh, 1990). These negative experiences in some cases result in part due to the professionals' failure to be able to communicate with these parents in a simple, effective and sensitive manner (Crown, 2009).

Financial impact of caring for a child with a developmental disability

Caring for a child with a developmental disability can have a direct influence over the finances of a family. As highlighted in the beginning of this chapter, families comprise the largest group of caregivers for children with developmental disabilities, however, these families receive very limited financial support to care for their child with developmental disabilities (Parish, Pomeranz-Essley, & Braddock, 2003). Parenting children with chronic illnesses or disabilities has some, but not pervasive, negative effects on economic well-being of families as conventionally measured by earnings and savings (Parish, Seltzer, Greenberg & Floyd, 2004). To be able to accommodate the needs of their child with disabilities, families may forego earnings because they spend less time in paid employment due to the caring needs of their child (Parish, Seltzer, Greenberg & Floyd, 2004). Caregiving demands were the most commonly cited reason for unemployment by mothers of adults with disabilities in a study by Eiman and Cuskelly (2002), the authors also found lower employment rates and fewer hours worked per week among employed mothers of children with disabilities. Consistent with these findings, studies have reported reduced maternal employment when a child has a disability or chronic health condition (e.g., Heck & Makuc, 2000; Kuhlthau & Perrin, 2001; Thyen et al., 1999) or reduced employment among parents of children with severe, but not moderate, disabilities (Lukemeyer, Meyers, & Smeeding, 2000; Wolfe & Hill, 1995).

Caring for a child with disabilities costs considerably more than for children without disabilities who are the same age (e.g., Davidoff, 2004; Guyot, & Cohen, 1990;Newachek & McManus, 1988). Parish, Seltzer, Greenberg & Floyd (2004), argue that it is not only the direct costs of parenting a child with disability which can affect a family's finances but also the effects of caregiving on other aspects of economic well-being, such as home equity, savings, and investments. They compared the economic well-being and maternal employment of parents whose children did or did not have developmental disabilities. They conducted this study using data from the Wisconsin Longitudinal Study. It was confirmed that the subsample of 61original Wisconsin Longitudinal Study mothers of children with developmental disabilities had patterns similar to those of the comparison group mothers. To examine differences in income, savings and investments, home equity, and mortgage amounts, the authors employed ranked analysis of covariance (ANCOVA) and regression analysis to examine the differences in home ownership and retirement or pension plans as these measures had binary outcomes. The results of this study revealed that the mean annual income of parents of children with developmental disabilities was considerably lower than the mean of parents in the comparison group. The results also showed that despite the fact that the two groups were similar at age 18, income and savings differed markedly by age 53, and that mothers of children with disabilities were less likely to have job spells lasting more than 5 years. This study, however, did not gather data on the severity of the children's disabilities even though it has been well documented that the time and financial costs associated with caring for children with severe disabilities is more extensive than those with milder disabilities (e.g., Birenbaum et al., 1990; Curran et al., 2001; Meyers et al., 1998; Worcester et al., 2008) and this could potentially limit the findings.

Literature documents that there can be both direct and indirect costs to families caring for children with disabilities. According to Stabile and Allin, (2012), direct monetary costs include expenditures such as on health care, therapeutic, behavioural, or educational services; transportation; caregivers; and other special needs services. Indirect costs consist primarily of reductions in parents' ability to sustain paid employment, therefore, parents of children with disabilities face unique financial challenges and hardships to be able to meet their child's special needs, making the process of parenting more stressful for these parents (e.g. Anderson et al., Curran et al., 2001; Davidoff, 2004; Dobson & Middleton, 1998; Hwang et al., 2001; Meyers et al., 1996).

Access to formal support services

It has often been suggested that the quality of life of these families is "highly dependent on the acquisition and maintenance of necessary support services" (McGarthy & Stough, 1999, p. 485). In a study conducted by Resch et al., (2010), examining the specific sources of challenges as identified by parents of children with disabilities, qualitative data revealed that amongst other factors, one of the most prominent barriers to positive parental wellbeing was access to information and services. The participants, all mothers, affirmed that access, or rather lack of access, to important information and services related to their child's health and well-being was the most salient and overarching area of concern for them, causing them considerable stress. The mothers in this research also noted that the signposting to relevant services and information was a particularly stressful process for them and a lack of communication and coordination among various agencies further complicated their ordeal of search for relevant information, advice and resources. In addition, the authors also found that the mothers considered the entire process of accessing services as a stressful and demeaning experience, due in part to the disrespectful treatment they often received. Similar findings and consequences of limited informal and formal social supports, and the negative impact of limited access to necessary services has also been reported by Egan &Walsh (2001) and Redmond & Richardson (2003). Overall, these studies suggest that parent stress and wellbeing is closely associated with a lack of match between their needs, and the information, resources, and supports available to them.

A methodological critique of existing studies

From the studies quoted in the section above it can be concluded that there is a prevalence of stress in parents caring for children with developmental disabilities. The studies quoted from existing childhood disability literature aim to address the issue of stress and coping in parents, but despite their strengths there are a number of methodological considerations which may have had an impact on these findings. A common limitation of studies in childhood disability is that the participants may be biased to report based on their expectations from a study. Research participants may be more inclined to participate or answer surveys, with the opinion that it may lead to a better understanding and better support for their families. There may also be a tendency to over report if participants are made aware that their responses in a study might lead to some sort of intervention development (Baranowski, Allen, Mâsse, & Wilson, 2006; Van de Mortel, 2008).This issue needs to be addressed in disability research and proper measures need to be taken to address this problem so the participants may truly reflect on and report their personal experience.

Many of the studies quoted in the literature review above relied on questionnaires and interviews where the researchers draw meaningful conclusions based on a true response from a study participant. However, this true response may be affected by the phenomenon of social desirability which results in participants trying to present a more favourable image of themselves (Johnson & Fendrich, 2005). The issue of raising a child with a developmental disability is a very sensitive one and research indicates that socially desirable responding is most likely to occur in questions which are deemed socially sensitive by the participant (King & Brunner, 2000). It can therefore be argued that socially desirable responding needs to be controlled for or minimised in studies exploring such sensitive topics so the parents may not feel pressured to gain social approval by trying to conform their feelings to the socially accepted ways of upbringing a child. This may be addressed, for example, by using questionnaires to detect social desirability (King & Brunner, 2000; Mortel, 2008).

Most qualitative studies mentioned in this review of literature-recruited participants purposively. This type of participant selection leads to the possibility that individuals who volunteer are fundamentally different, and perhaps more active and involved as compared to their counterparts who chose not to be a part of the study, which may limit the results being generalized (Etikan, Musa & Alkassim, 2016). The nature of purposive sampling therefore may significantly impede the researcher’s ability to draw inferences about a population. This self-selection bias often has repercussions in the issues concerning sampling representativeness and generalizability (Braver & Bay, 1992); Costigan & Cox (2001), advocate that evaluating this bias in studies can be problematic due to the fact that the researcher typically does not have information about the nonparticipants and therefore cannot compare them with the participants. To overcome this problem, researchers suggest using comparative designs or designs that require participation of both parents (e.g.

Rueter & Conger, 1995); however, this may significantly impede the research participation rates which are considerably low among this population.

Another problem related to participation bias in such studies is the difference in participation rates for mothers and fathers (Costigan & Cox, 2001; Phares, Fields, Kamboukos, & Lopez, 2005; Zimmerman et al., 2000). Research suggests that in families of disabled children mothers are far more likely than fathers to take on the major caring role for their child, and are less likely to be in paid employment (Macfadyen, Swallow, Santacroce, & Lambert, 2011). Due to their high stakes in the caring role for their child, mothers are most involved in research studies (Gordon et al., 2007; Joseph Rowntree Foundation 2001; Miles & Huberman, 1994; Scott, 2010; Shearn and Todd, 2000; Warfield, 2001). However, this limitation should not significantly restrict the result studies of this kind as mothers are typically the primary care providers for children with disabilities. It needs to be reinforced in studies, that crucially, this focus on mothers is not intended to diminish the importance of the views of the fathers but rather offer a practical solution to this problem. However, this evidence of underrepresentation of fathers in disability research needs to be addressed and an equally clear need for a change in this pattern needs to be implemented.

A common limitation in many studies of this nature as quoted above, is the tendency to administer tests / questionnaires just once (e.g. Hassall, Rose & McDonald, 2005; Olsson & Hawang, 2001; Podolksi & Nigg, 2001; Smith, Oliver & Innocenti, 2001) and hence the overall results and conclusions may be entirely based on this single administration of the questionnaire. Folkman & Lazarus (1985), in their phenomenal work explain that a stress is not a unitary static event, it is rather an unfolding process and thus should be measured in this way. Studies therefore, should aim at understanding the complex nature of stress and coping preferably by using repeated measures and structured interviews to increase knowledge about the momentary properties of stress and to understand human adaptation to this phenomenon (Folkman & Lazarus, 1985).

Many studies investigating stress and coping in parents of children with developmental disabilities base their findings on either quantitative data collection by the use of self-administered questionnaires (e.g. Curran et al., 2001; Gallagher et al., 2010; Greenberg & Floyd , 2004; Urbano & Hodapp, 2007; Worcester et al., 2008) or qualitative data collection exclusively relying on interviews (e.g. Murphy, Christian, Caplin & Young,2007; Resch et al., 2010; Resch, Elliott, & Benz, 2012). However, in order to increase knowledge about stress in parenting and factors affecting it, quantitative questionnaire results should be supplemented with qualitative data for the researcher to draw verifiable findings (Beresford, 1994; Hall et al., 2012). This way qualitative data gathered can be used to gain a deep understanding of the parents' views and statistical analysis can provide detailed assessment of the quantifiable responses (McCusker & Gunaydin, 2015). Mixed methods research can be particularly useful in such sensitive psychological research, as only a broader range of perspectives can do justice to the complexity of this phenomena of stress and coping (Foss and Ellefsen, 2002; 1992; Tashakkori & Creswell, 2007).

A lot of research in the field of childhood disability focusses on the adverse outcomes of disability on the family however, the positive adaptation of parents of children with developmental disabilities needs to be acknowledged too as this may mediate the process of stress and coping considerably. This review of literature clearly indicates that parents of children diagnosed with a developmental disabilities face great challenges with the unusual developmental progress of their child (Schuntermann, 2002) and are more prone to distress as compared to parents of typically developing children (Knapp, 2005; Smith, Oliver & Innocenti, 2001; Spratt et al., 2007). However, research also reveals that as parents deal with the challenges of raising their children with disabilities, they also come to see their situation in a positive way. They consider having a child with a disability as a life changing experience that prompts them to appraise their belief systems, values, and priorities, resulting in a new way of seeing their lives or reappraising their situation (Gray, 2006; Green, 2007; Hastings & Taunt, 2002; King et al., 2006). Substantial research in childhood disability aims to recognise the positive influence that a child with a disability can have on the life of their family (e.g. Folkman &Moskowitz, 2000; Green, 2007; Hastings, Allen, McDermott, & Still, 2002; Hastings & Taunt, 2002; Flaherty & Glidden, 2000; Hastings, Beck, & Hill, 2005) rather than dwelling on the high levels of pathology associated with childhood disability. The approach to “disability” has changed over time and literature on childhood disability is increasingly focusing on variability, adaptation, and resilience (e.g., Green, 2007; Seltzer et al., 2001; Turnbull et al., 2000) in contrast to the well-established and pervasive narratives of grief, trauma, suffering and stress. The arguments now focus on positive adaptation, quality of life, and recognising the benefits of having a child with a developmental disability in the family (e.g., Bennett, DeLuca, & Allen, 1996; Hastings & Taunt, 2002; Gupta & Singhal, 2004; Poston et al., 2003; Summers, Behr, & Murphy, 1992). In line with this chain of thought, the following section highlights how despite the high levels of stress, parents of children with developmental disabilities try to adapt a more positive outlook towards their situation.

Positive Adaptation in Parents Caring for Children with Developmental Disabilities

According to King et al., (2006), most studies do not consider the positive outcomes or contributions of having a child with developmental disabilities at home. Kayfitz, Gragg and Orr (2010), also report that most literature focused on parenting children with developmental disabilities has been centred on the realm of the negative aspects of raising these children such as stress, anxiety or depression amongst others. However, it is argued that with changing times the interpretation of the meaning of having a child with a developmental disability has evolved for the better. Positive adaptation such as greater appreciation of life (Kausar, Jevne & Sobsey 2003) and developing personal qualities as tolerance, compassion and patience have been reported by many parents (Scorgie and Sobsey, 2000). So, despite a large majority of literature suggesting that caring for a child with a disability can have profound effects on the family and it’s functioning, psychologists argue that being a part of this situation can increase the family members' awareness of their inner strength, enhance family cohesion and broaden their perceptions and thoughts (Reichman, Corman & Noonan, 2008).

Research suggests that there is a wide range of family response to disability, which includes positive adaptation in which families are strengthened and children with disabilities are viewed as contributors to the family’s quality of life (Ferguson, 2001; Green, 2007). Research also reveal that many parents adapt to the emotional and caregiving challenges of looking after a child with a developmental disability with positive coping, adaptation and resiliency (Goodley & Tregaskis, 2006; McKeever & Miller, 2004). Indeed, most mothers of children with disabilities perceive valuable benefits in having a child with a disability (Green, 2007), and a growing body of research indicates that many parents of children with disabilities experience joy, greater sense of meaning and purpose in life, and other positive outcomes (Stainton & Besser, 1998; Blacher & Baker, 2007; Green, 2007).

According to Lawton et al’s., (1991), two-factor model of caregiving, there is a coexistence of both negative and positive outcomes of raising children with developmental disabilities. Their model proposes that there are two independent pathways leading to caregiving outcomes, first, which include the difficult characteristics of the cared for individual (e.g. extent of dependence or behavioural problems) which act as stressors for the carer and result in negative outcomes. Second, the perceived positive characteristics of this cared for person (e.g. adaptive skills or ability to form relationships) which can be related to positive caregiver outcomes (Lawton, Moss, Kleban, Glicksman & Rovine, 1991). Studies of parents of children with developmental disabilities fall well within this model of caregiving as they experience both positive and negative outcomes. Evidence suggests that people may improve their psychological wellbeing and physical health by propagating experiences of positive emotions at occasions to cope with some of their negative emotions (Fredrickson, 2001).

According to Tugade & Fredrickson (2004), positive emotions help to ease stress and can lead individuals to finding positive meaning in stressful situations. It has been established that a conscious awareness of positive emotions depicts psychological resources that can reinforce the process of adaptive coping with stressors (Folkman and Moskowitz, 2000, Fredrickson, 2001). Using the technique of content analysis Mullins (1987), identified various themes arising in 60 books written by parents of children with various developmental disabilities; the major themes he identified included emotional stress and caregiving demands on one hand

and the enrichment of lives and increased fulfilment on the other. In a somewhat similar analysis of fathers' published accounts, Hornby (1994), identified themes of positive feelings, meaningful lives and claims of personal growth. Some families with children, who have developmental disabilities, may adapt to situations and change attitudes over time which may lead to their successful adaptation of the situation (Cowan, 1991). Grant (1993) explored this phenomenon in his study and identified that the 'cared for' individual gradually becomes a source of motivation and support resource for the parents thereby leading to better family adaptation over time.

It is beyond doubt that in most cases parents struggle to overcome their 'lost dream' but positive adaptations occur in the form of changed views of life and disability and the realization of the positive contributions that the child brings (King et al., 2006). In addition to positive emotion, supplementary studies indicate a positive relationship between the mothers' positive appraisal of their children's disability and perceived family adjustment (e.g. Trute et al., 2010; Trute & Hiebert-Murphy, 2002; Hastings et al., 2005b). Kayfitz, Gragg, and Orr (2010) examined the impact that positive experiences had on parents of children with autism. Their research concluded that parents who perceived the contributions of their child more positively experienced lesser parenting stress. The authors thus theorized that a more positive approach towards their child enables parents to minimise their attention to the child's limitations and, thus, potentially pay less attention to their limitations as parents, which in turn offers protection against a negative sense of well-being.

Psychological Interventions for parents caring for children with developmental disabilities

The evidence reviewed thus far in this chapter clearly indicates that providing care for a child in the family who has a disability is undoubtedly challenging with a significant psychosocial impact on the caregiver. However, literature also suggests that if the parents are equipped with efficient coping techniques, these challenges are not impossible to overcome (Paster, Brandwein & Walsh, 2009). The evidence discussed in the previous section highlights the potential for stress amongst parents who are dealing with the chronic stress of caring for a child with a long term developmental disability, however, findings from contemporary studies are indicative of the variability in parental adaptation in families of children with disabilities (Glidden & Schoolcraft, 2003; Singer 2006).

As a result of the stresses associated with caregiving for children with disabilities (e.g. Hastings & Beck, 2004; Knapp, 2005; Spratt et al., 2007) it is key to aim for preventive and restorative outcomes for parents and family members (Singer, Ethridge & Aldana; 2007) which may assist in reducing their levels of distress and promoting well-being. The experience of caring for a child with a disability may also lead to strengthening the families once they are equipped with appropriate coping strategies to assist them through difficult situations (Summers, Behr, & Turnbull, 1989). Studies reveal that a family can develop into a stronger functional unit if they have ample coping strategies giving them more control over the situation they are in (Abbott and Meredith,1986).

Coping research reveals that psychological interventions that enhance coping, result in better adaptation to the stressful situation (Coyne & Racioppo, 2000; Leake, Friend & Wadhwa, 1999) and that effective interventions can help to reduce symptoms of stress in parents of children with developmental disabilities (Singer, Ethridge, Aldana; 2007). Several researchers have studied interventions designed to enhance well-being and reduce depressive symptoms in parents of children with developmental disabilities and in most cases have consistently established benefits (Hastings & Beck, 2004; Singer et al.; 2007), indicating the credits of using interventions for this sub-group.

A number of interventions have hence been designed and implemented in the past in an effort to minimise the potentially negative psychological consequences and promote positive outcomes for parents caring for children with developmental disabilities. These interventions can broadly be divided on the basis of the theoretical approach they are based on such as behavioural component training (e.g. Sofronoff, Leslie,& Brown, 2004), stress management (e.g. Bitsika & Sharpley, 2000), cognitive behavioural therapy (e.g. Gammon & Rose, 1991), parent empowerment training (e.g. Sofronoff & Farbotko, 2002) or mindfulness (e.g. Neece, 2014) amongst others.

Research also highlights the significance of promoting coping processes that help in maintaining positive psychological states whilst encountering a stressful situation (Folkman, 1997; Folkman & Moskowitz, 2000). Pearlin and Schooler (1978) evaluated the efficacy of coping behaviours and concluded that the style and content of coping behaviours can influence the well-being of an individual, they also suggested that the more the scope and variedness in the coping response, the more protection an individual has against the threat of stress. Consistent with these findings there have been a multitude of coping interventions designed for the families of children with developmental disabilities. When viewed as a whole, intervention studies have consistently demonstrated benefits in terms of supporting parents and remediating parenting stress (Hastings & Beck, 2004; Hudson et al., 2003; Singer, Ethridge, & Aldana, 2007). This evidence is encouraging and is a clear indicator that many parents of children with developmental disabilities are responsive to supportive interventions (Hasting & Beck, 2004; Singer et al., 2007).

Research also supports a reasonable evidence base for the use of CBT techniques in improving the well-being of parents of children with developmental disabilities (e.g. Greaves, 1997; Levy et al., 2003; Nixon & Singer, 1993; Singer et al., 2007). A randomised controlled trial by Gammon and Rose (1991) used the CBT approach with groups of four to eight mothers meeting for a two-hour session once a week for 10 weeks. Their intervention focussed on cognitive restructuring, enhancing problem-solving skills, setting individual goals, training interpersonal skills, and encouraging interaction amongst group members. The authors concluded that there was a greater reduction in stress in comparison to the no treatment group. They also found some evidence of improved problem-solving and interpersonal communication skills (as assessed in role-plays) in the treatment group. Greaves (1997) also based his intervention on the Cognitive Behavioural Therapy approach and reported reduced stress in mothers using the intervention which composed of eight weekly group sessions focusing on core irrational beliefs and hypothesised links with stress. The mothers were trained on disputing irrational beliefs and replacement of these with rational beliefs as a part of the intervention. Singer et al., (1994, 1988), created an intervention for parents based on CBT providing psychoeducational instruction of coping skills and parent-to parent self-help and social support (1994) and stressful event and physiological reaction self-monitoring, muscle relaxation skills, and modification of cognitions associated with distress (1988). Both the studies showed a significant reduction in depression and anxiety symptoms.

Some of the other successfully implemented interventions in this group of parents are based on Multiple Component Therapy (MCT) (Singer et al., 1994), which as the name states comprise of various components of stress management interventions which include Behavioural Parent Training (BPT), CBT and or other support services working towards a single goal of stress management (Singer, Ethridge & Aldana,2007). Studies have also revealed that there have been significant differences in parenting knowledge, attitudes and self-efficacy after receiving interventions such as BPT (Lundahl et al., 2006).

An MCT intervention designed by Bristol et al., (1993) included teaching aspects of child behaviour management, individual coaching, counselling and parent environmental management. Another MCT based intervention with promising results was designed and implemented by Tonge et al., (2006), which worked by coaching parents in behaviour management skills training and educating them about autism, social interaction, communication, mental health etc. In their meta- analysis of group-intervention research Singer, Ethridge, &Aldana (2007) found out that Multiple Component interventions are clearly more effective than Behavioural Parent Training or Cognitive Behavioural Therapy when offered on their own. However, these approaches have been criticised by researchers as potentially exacerbating stress by placing additional demands and expectations on the parents (Gallagher, Beckman & Cross, 1983).

Other researchers have used methods such as ‘signposting’ (a system designed for parents where an intervention can be delivered via one to one support, telephone, group support or through a self-directed mode) as interventions. For example, Hudson et al., 2003, advocated that signposts is a flexible intervention system for families of children who have intellectual disability and challenging behaviour. In their study the authors used signpost materials designed for parents in the form of core booklets, workbooks and videotapes. This intervention was intended to be self-help in nature as the parents were given instructions to follow, for them to be able to reduce their levels of stress and manage their child's problematic behaviour. The results revealed that after using the Signpost materials the parents reported as feeling less stressed and less hassled and more efficacious about managing their child's behaviour. Families using this intervention also reported high levels of satisfaction with the way this intervention was delivered. Hence, the authors concluded that self-help materials can be successful in meeting the needs of families due to the flexibility and freedom they can give to the individuals using them.

Some researchers advocate the use of child focused interventions which mainly focus upon reducing problem behaviour and thereby reducing a parent's stress level (e.g. Baxter, Cummins, & Yiolitis, 2000, Carr, 2009). As discussed in the previous section, child characteristics such as child behaviour, are an important predictor of care-giver stress and there is substantial evidence pointing towards associations between the severity or frequency of behaviour problems of children with developmental disabilities and parental stress and other minor mental problems such as depression and anxiety (e.g., Baker, Blacher, Crnic, & Edelbrock, 2002; Baxter, Cummins, & Yiolitis, 2000). Evidence also suggests that there is a bidirectional effect where the child's behaviour problems predict parental stress over time, and parental wellbeing predicts child behaviour problems over time (Baker et al., 2003; Orsmond, Seltzer, Krauss, & Hong, 2003). These interventions are mainly guided by the principle that irrespective of whether the outcome of stress is child-driven or bidirectional, reducing the child's behaviour problems should result in reduced parental stress. Many studies hence have evaluated the outcomes of such child-focussed interventions, for example, in a randomised controlled trial by Wiggs and Stores (2001), the authors assessed the mental state of parents following a behavioural intervention in children with severe intellectual disabilities, sleep problems and challenging behaviour. The behavioural intervention comprised of a number of visits to the family exploring the child's problem, identification of the parents' aim of treatment and explaining to them about the various therapeutic techniques they could choose from depending upon their expectations and their child's needs. They found out that the intervention led to not only improvements in the children's and parents' sleep, but also for reductions in stress reported by mothers. However, no change in stress was reported in this study by fathers as a result of the sleep intervention.

Feldman and Werner (2002), and Sofronoff and Farbotko (2002), showed that parents trained in behavioural principles reported increases in their self-efficacy in managing their child's behaviour and lower levels of stress. However, it is argued that behavioural parent training approaches do not consistently result in reductions of parenting stress especially in fathers (Singer, Ethridge, & Aldana, 2007).

There have also been a multitude of studies which have offered group or family interventions to parents of children with learning disabilities, these interventions are of an educational-didactic nature (Anastopoulos & Farley, 2003). In such interventions, the parents are briefed about the unique complications of their child's diagnosis in all areas of day to day functioning, and training in coping skills is provided specifically focussed on the behavioural problems of the children. Such interventions are successful at reducing child problem behaviours and therefore benefit parental well-being (Baker et al., 2002; Baxter, Cummins & Yiolitis, 2000); however, these interventions do not directly aim at reducing the parents stress levels, which may be heightened due to various additional factors other than the child's problem behaviour. As a consequence, the effects of this kind of an intervention which is child driven and aims at reducing their behaviour problems, focuses less on the parents' emotions and stress and more on the issues related to child behaviour (Schehtman & Gilat, 2005).

Thus, it may be argued that if these parents can be helped by managing their coping mechanisms effectively, they can in turn better manage their levels of stress and the demands of parenting a child with a developmental disability. Hastings and Beck (2004), recommend that when parents are under stress they may be less tolerant of their child's problematic behaviour and hence may not be able to make any active attempts to reduce this behaviour, therefore implementing a stress reduction intervention prior to using a programme designed to focus on child behaviour may improve the efficacy of the latter.

Other forms of successfully implemented interventions in the past include techniques such as benefit finding. Finding benefits and expressing emotions in relation to stressful experiences have been associated with positive adjustment (LaPlante, 2013; Stanton et al., 2002) and as a form of cognitive adaptation which allows individuals to positively evaluate their circumstances, thereby minimising the negative implications of the experience (Taylor, 1983). However, in any respect, it is important to endorse cautions against interventions promoting sole focus on positive thinking as in certain cases for example chronic illnesses such as a congenital heart disease or cerebral palsy, a superficial urge on positive thinking may lead to maladaptive forms of avoidance coping (Lutgendorf et al., 1999). In addition, imposing the suggestion of distinct benefits for positive thinking may be perceived as ‘insensitive’ or as ‘minimising the affected person’s experience’ (Affleck & Tennen, 1996) from the parents’ point of view.

However, benefit finding prompts people to self-generate benefits based on their present situation. Researchers have found that parents of children with disabilities and medical illness report benefits from their adversity including personal growth, strengthening of relationships, and changes in goals and life’s priorities (e.g., Affleck, Tennen, & Rowe, 1990, 1991; King & Patterson, 2000; Pakenham, Soronoff & Samios, 2004). In their study exploring the relationship between benefit finding and stress amongst parents of children with Asperger syndrome, Pakenham et al., (2004), found that benefit finding is an important and constructive process that is integral to coping with raising a child with a developmental disorder. The authors recommended that future interventions should employ cognitive restructuring techniques to enhance benefit finding and sense making amongst parents caring for children with a developmental disability.

Interventions such as expression of ‘gratitude’ have also been used for coping with stress and adversity. According to Wood, Maltby, Gillett et al., (2008), “….Gratitude is a quintessential positive psychological trait and involves a life orientation towards the positive in the world”. Research indicates that the regular experience and expression of gratitude may be helpful in building personal and interpersonal resources for coping effectively with stress and adversity (Bono et al., 2004). Based on complimentary longitudinal evidence that supports gratitude as a precursor of well-being, gratitude interventions in disability research have been developed and implemented. These interventions have been highlighted as relevant, cost effective and manageable techniques which make an individual more likely to behave in a more socially productive manner (for example, Bono et al., 2004; Dykens, 2015; Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014). However, an important caveat to implementing these interventions is that appreciating the positive in life is a dispositional tendency, therefore, considerable individual differences may exist in understanding this trait.

Other successfully implemented interventions include techniques such as 'worry postponement'. Parents who ruminate on current problems, for example the severity of the diagnosis of their child, may experience more pessimistic views of the future and thus become more vulnerable to psychopathology (Ogston, Mackintosh, & Myers, 2011). Too much worry may lead to experiencing negative emotions, which further manifests to negative affective conditions (Abbeduto et al., 2004; Lyons, Leon, Phelps, & Dunleavy, 2010). Therefore, this finding has important implications for treatment in that mitigating negative thinking through cognitive therapy should be an intervention priority for this population of parents. Brosschot and Van Der Doef (2006), tested the effectiveness of a simple worry reduction intervention on one hundred and seventy one high school students by introducing a simple postponement intervention where the participants were instructed to try to postpone their worrying time every time they realized they were worrying, to special 30-minute period late in the evening that they would reserve for worrying. The researchers expected that this brief postponement intervention would lead to less worrying and less somatic complaints eventually. The results in line with the expectations showed that the postponement intervention reduced the worry duration as well as the frequency of somatic complaints. The results also indicated that this intervention led to a stronger reduction in worry duration (nearly 32 %) in comparison to worry frequency (of about 21%). These findings were consistent with the aim of the study which was to postpone the worry but not to prevent it from occurring. Brosschot and Van Der Doef (2006), hence suggest that it may be an easier option to help individuals to restrict the amount of time they spend on worrying rather than attempting to decrease the frequency with which worries appear in awareness. This study had a major limitation as the sample was restricted in terms of age and in gender (15-19 years old; 18.6% male and 81.4% female), therefore, for these results to be generalised a similar study needs to be replicated in a wider population.

In recent times, emotional expression through ‘expressive writings’ (Whitney & Smith, 2014) and ‘journal writing’ have also been recognised as types of interventions. Expressive writing is a typically involves writing about a stressful or traumatic event over a period of few days (Gellaitry et al., 2010). Various studies have concluded that this is an effective way of coping (Campbell, 2003; Duncan et al., 2007; Gellaitry et al., 2010; Frattaroli,2006). Duncan et al., (2007) have used this paradigm in their work with parents of children diagnosed with cancer; this intervention resulted in a decrease in parental posttraumatic stress symptoms but no change was registered in parental depression.

Another simple form of emotion-focused coping that may be used as an effective intervention to help parents to reduce their day to day levels of distress is ‘distraction’. Nolen-Hoeksema & Morrow (1993) define distraction response as a purposeful diversion of attention away from symptoms of depression onto pleasant or neutral thoughts and actions. Based on the kind of distraction technique used it may lead to various outcomes, for example, relaxation or deep breathing may be effective in reducing physiological pain; whereas, other distraction based activities such as watching a favourite television series may reduce the frequency of intrusive thoughts. Bennett et al., (2007), evaluated the effectiveness of a distraction based coping leaflet on women who were awaiting genetic risk information. Amongst other techniques, they encouraged participants in their study to limit any consideration of issues related to their risk assessment (main stressor) for clearly defined periods each day (e.g., 10–15 min), and to actively distract from any intrusive thoughts at all other times. The results of this study suggested that such an intervention is appropriate for individuals who experience distress whilst waiting for potentially adverse personal health information.

Despite being relatively simple and easy to administer, distraction has not been studied as a form of coping mechanism for parents of children with developmental disabilities.

In other fields, numerous studies report that engaging in a distraction task decreases depressed mood and increases pain threshold (Branstetter-Rost, Cushing & Douleh, 2009; Butler & Nolen-Hoeksema, 1994; Nolen-Hoeksema & Morrow, 1993; Paez-Blarrina et al., 2008; Trask & Sigmon, 1999). Effective distraction according to Nolen-Hoeksema (1991) should be engrossing and have a high probability of positive reinforcement to the individual. Adapting to engage in benign distracting activities where individuals are encouraged to engage in specific behavioural or cognitive tasks as soon as they experience intrusive thoughts to manage periods of negative mood may be an important step for parents to cope with their day-to-day stress.

‘Mindfulness’ based stress reduction has also been used as a psychological intervention in group intervention programs over the last two decades (Grossman et al., 2004). This intervention approach is based upon a systematic psychological process to develop enhanced awareness of perceptible mental states and processes, assuming that greater awareness would provide more veridical perception, reduce negative affect and improve coping. Several mindfulness interventions (e.g., mindfulness-based stress reduction, MBSR) have undergone extensive research showing their effectiveness in reducing general stress, anxiety, depression, promoting overall well-being and improving psychological functioning (Baer, 2003; Bazzano et al., 2015; Grossman, Niemann, Schmidt, & Walach, 2004).). Various studies have concluded that mindfulness based interventions are successful in significantly decreasing substantial stress symptoms and mood disturbance in parents caring for children with chronic conditions (Ferraioli and Harris 2013; Jones, Hastings, Totsika, Keane, & Rhule 2014). Similarly, studying the effects of relaxation, preliminary tests of the effects of self-applied breathing and guided imagery relaxation techniques for primary caregivers of chronically ill children have also shown positive outcomes (Hernandez & Kolb, 1998). Even though mindfulness has been established as an effective psychological intervention for parents struggling to cope with the care for a child with a disability, it is likely that this form of intervention may only appeal to a small cohort of parents. Reason being that to undertake this training would require an individual to be highly committed and motivated to follow this practice for long term to be able to experience the results. There is a lack of evidence in current disability literature suggesting as to how intensive a mindfulness intervention must be to result in significant reductions in stress regardless of the severity of risk in the population of interest. It is also worth noting that mindfulness-based interventions may vary widely with regard to duration, intensity, format, setting, and content; and different studies tend to examine different mindfulness interventions often failing to provide sufficient details of the interventions provided, therefore, it is difficult to replicate these interventions and aggregate findings across studies (Crnic et al., 2017).

The review of literature above indicates that implementing any form of structured interventions appear to have a positive impact over no support or the receipt of standard services to parents caring for children with developmental disabilities. The interventions reviewed certainly address some facets of parental stress, for instance dealing with caregiving demands, communication problems or social supports. However, they do not explicitly aim at helping parents to enhance their own personal coping skills, which may help them to prepare for and develop resilience against present and future stress. According to Bailey, Buysse, Edmondson, and Smith (1992), children and families are inextricably intertwined and influence each other. Whether intentional or not, interventions with children almost invariably influences families; likewise, interventions with families almost invariably influence children. Therefore, involving and supporting families is likely to be a more powerful intervention than one that focuses exclusively on the child. (p. 299). It is also vital that interventions should be directly aimed at parents. Hastings and Beck (2004), recommend that when parents are under stress they may be less tolerant of their child’s problematic behaviour and hence may not be able to make any active attempts to reduce this behaviour, therefore implementing stress reduction interventions prior to using interventions designed to focus on child behaviour may improve the efficacy of the latter.

There is much evidence in the family coping and support literature about the importance of learning effective coping strategies to lessen the negative effects of stressors that can accompany having a child with a disability (e.g. Abbott and Meredith (1986); Duncan et al., 2007; Paster, Brandwein & Walsh, 2009; Summers, Behr, & Turnbull, 1989). Literature suggests that parents who are not able to cope well with their caring role, have low self-esteem, anxiety, depression, stress, and marital unhappiness (Bright, Hayward, & Clements, 1997; Forde et al., 2004; Oelofsen & Richardson, 2006; Olsson & Hwang, 2001) and hence require interventions to support them in a timely manner.

It can thus be argued that parents of children with developmental disabilities may have varying levels of parental stress (Glidden & Schoolcraft, 2003), and parents with considerable stress may find it difficult to make long-term parenting behaviour changes. Therefore, they must be introduced to interventions that can help them to deal with the daily stress of their caring role.

Summary

This chapter provides an overview of the experience of parenting a child with a developmental disability. The first half details the implications of the child's disability and the profound effect this can have on the parents' well-being, leading to high levels of stress and a variety of discomfiting and intense affective experiences. Per contra, the chapter also highlights the numerous positive effects many parents of children with developmental disabilities experience. The literature review indicates that some parents may cope better than the others in the same situation, as they are able to effectively identify and utilise coping mechanisms thereby minimising their levels of stress. The chapter also discusses the importance of positive emotions as an effective coping mechanism highlighting the significance of positive adaptation in the lives of parents who have a child with a developmental disability. It further critiques the different types of interventions available to families with disabled children. The following chapter will provide a critical appraisal of the theoretical framework and psychological evidence underpinning this research and take an in-depth look into the nature of stress and coping and establish how these may provide a better understanding of the way in which parents differ in the way they perceive and cope with the stress of caring for a child with a developmental disability. Given the importance of ensuring interventions are based on sound theoretical underpinnings, the specific focus and structure of the intervention developed through this thesis will be described in Chapter Four, which is preceded by a critical review of the current context of stress and coping theory in the following chapter.

CHAPTER 3

Psychological theories of stress and coping: theoretical review

The aim of this chapter is to critically explore how well psychological theories of stress and coping can explain the experience of parents caring for a child with a development disability, leading to a justification for the specific theoretical framework underpinning this thesis. The chapter will therefore commence with a broad introduction to current conceptual definitions of stress and coping, before critically discussing a number of general and specific models of stress and coping that offer a psychological framework within which to understand the complex interplay between situational factors, individual differences and stress and coping responses in parents of children with development disabilities. This theoretical review will then justify and defend the choice of the specific theoretical framework, that of Lazarus and Folkman's transactional mode (1984), for underpinning this thesis.

The field of stress and coping research has received significant attention from psychologists over the last thirty or so years, with stress now being recognised as being associated with a wide range of physical and mental health problems across clinical and non-clinical populations and cohorts of interest. Moving away from earlier models of stress which viewed stress as a response (Selye, 1956), as a stimulus (Holmes & Rahe, 1967), or an external force or demand on the person (Breznitz & Goldberg, 1993); current conceptualisations acknowledge the role of psychological factors in the stress process and the combined effect of multiple stressors on people's psychological and physical functioning. In a critical review of the psychological literature in this field, Segerstrom & Connor (2012), highlight that despite the depth and breadth of research into stress, coping and health over the last three decades, the different models and conceptualisations of stress and coping, and associated measurement issues, mean that there remain significant challenges in the field. Tennen, and Affleck (1998), argue that much of research views coping in an unidirectional and static way, despite the fact that coping can lead to changes in adaptational outcomes, which then lead to changes in subsequent appraisals, coping, or external contingencies on behaviour. They debate that this transactional nature of coping though significant is difficult to capture and interpret. Accordingly, the following section will firstly attempt to conceptualise stress and coping in reference to the current empirical literature, before reviewing some of the most popular models of stress, coping, and providing a justification for the specific theoretical framework of Lazarus and Folkman's transactional model that is employed in this thesis. As the early pioneers promoting psychological understanding of stress and coping, the work of Lazarus and colleagues will inevitably be alluded to across this chapter, with a critical review of the model and evaluation of alternative models forming the main part of this chapter.

Stress cannot be studied as a unitary variable as it has different causes or sources and can differ in intensity and manifestations. It has hence been identified as a unified system of interdependent processes (Lazarus, DeLongis & Folkman, 1988), which include, the causes of stress, appraisals, the coping mechanisms, the mediators of stress and the intensity and the manifestation in terms of psychological and somatic responses (Pearlin, Menaghan, Lieberman & Mullan, 1981; De Longis, Lazarus & Folkman,1984). Monat and Lazarus (1991) explain that stress is a complex interplay between individuals and their environment; and in broad terms “refers to any event in which environmental demands, internal demands, or both, tax or exceed the adaptive resources of an individual, social system, or tissue system.” (Monat & Lazarus, 1991, p. 3).

Lazarus and Folkman (1984) approach the effect of an event from the perspective of the person experiencing it. They describe stress as a process involving continuous interactions and adjustments called ‘transactions’ between the person and the environment; the person therefore is the active agent who can influence the impact of a stressor through behavioural, cognitive and emotional strategies. Taylor (1999), agrees with Lazarus (1993), and adds that stress is “the consequence of a person’s appraisal processes: the assessment of whether personal resources are sufficient to meet the demands or the environment” (p.169). However, appraisals of the demand are relative to one’s resources, degree of threat or challenge and hence whether this event is experienced as stress will depend upon the person (Segerstrom & Connor, 2012). For example, two people may experience the same circumstances but different appraisals may lead to stress in one but not the other. Segerstrom & Connor (2012), explain that the cascading effects of stress are difficult to capture explicitly, for example, a major stressor which is the caring role of parents in this thesis may have (i) stressor consequences e.g. financial and social stressors, (ii) perceived stress consequences e.g. sense of uncontrollability overall, and (iii) distress consequences e.g. anxiety or depression.

To escape this cascade of stress many studies focus on coping, which is a reaction to the circumstances of a stressor and its consequent emotions. People use their ability of coping as an important mediating resource to counter stress, which includes specific behaviours that an individual displays as a result of an unpleasant situation. The goal of coping is to strengthen or maintain family resources, protect the family from the demands of stressful encounters (Judge, 1998), reduce the sources of stress or negative emotions (McCubbin, 1979), and achieve a balance in family functioning (McCubbin et al., 1980). However, the coping strategies that parents may use to manage this stress may differ from one parent to another. This may depend on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event (Lazarus, 1991; Lazarus & Folkman, 1984) and the family's sources of support, resources, and family structure (Bailey & Smith, 2000; McCubbin & Patterson, 1983). The functions of coping can be divided into categories based on their operational bases, for example, creating a stable psychological equilibrium to meet external demands; reducing or eliminating harmful environmental conditions; reducing existing psychological stress; maintaining a positive self-image and promoting self-well-being (Cohen & Lazarus, 1979; Haan, 1977;Pearlin & Schooler, 1978).

According to Folkman (2012), coping provides an insight into the way people survive the challenges of daily living, and is one of the few variables in the stress process that lends itself to interventions. Both stress and coping are interlinked in various psychological theories as coping is hypothesized as a mediator of the effects of stress on mental and physical health.(Folkman, 2012). In reference to raising a child with a disability, parental stress is partially mediated via parental coping strategies (Hastings, 2002, McCubbin & Patterson, 1983; Quine & Pahl, 1991) which makes it important to understand the implications of such stress and parental coping and to identify how these processes are interlinked. One of the most prominent theories of stress and coping which can aid our understanding of this process is the renowned transactional model of stress and coping proposed by Lazarus and Folkman (Lazarus & Folkman, 1984; Folkman & Lazarus, 1988), this theory can add immensely to the understanding of stress process and coping response in parents of children with developmental disabilities.

The Transactional Model of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984; Folkman & Lazarus, 1988)

The transactional model is an appraisal-based model; it highlights the role of cognitive processes and emotional reactions that underpin an individual's interaction with his or her environment and regards stress as a mutually reciprocal, bidirectional and dynamic transaction between an individual and the environment (Lazarus & Folkman, 1984; Folkman & Lazarus, 1988). This model identifies two distinct but interrelated constructs as mediators in a stressful encounter, these are, cognitive appraisal and coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). The core assumption of this model is that the stressful experience is shaped through the cognitive mechanisms of appraisal and coping. As Lazarus (1999) points out, "It is the meaning constructed by a person about what is happening that is crucial to the arousal of stress reactions." (Lazarus, 1999, p. 55). Lazarus (1984) hence theorises that evaluative thoughts of cognitive appraisal and coping can influence the impact of stress or the degree of the stress reaction on an individual. The next section details cognitive appraisal as a key aspect of this transactional model.

Cognitive Appraisal

According to the transactional model of stress and coping, a fundamental part of the stress and coping process is cognitive appraisal. The term cognitive signifies an individual's cognitive evaluation of a particular interaction for his or her well-being. It is a central process leading to coping and emotions and is conceptualised as a mediating variable between the stressor and available resources. Distinctions need to be made by individuals in order to flourish and survive situations which require appraising these situations as potentially dangerous or benign. To study these distinctions in individuals under similar conditions, it is important to take into account the process of cognitive appraisal that mediates between the encounter and the reaction. Lazarus (1993), elaborates the process of appraisal as the process that negotiates between, "the demands, constraints and resources of the environment; and the goal hierarchy and personal beliefs of the individual" (p.6). Cognitive appraisal helps an individual to gauge if his or her relationship with the environment is of value or is meaningful and if that is the case, in what way that is so (Folkman & Lazarus, 1984). Hence, cognitive appraisals play an important role in the choice of coping strategies employed by an individual.

According to the transactional model, the primary appraisal stage leads an individual to determine if a transaction with the environment is of potential benefit or harm to them; thereby leading an individual to evaluate what is at stake in the given scenario (Folkman et al., 1986). An individual may perceive their transaction with the environment as being beneficial or relevant depending upon factors such as personal goals, values and so forth. This decision is based on two very specific appraisals one of which is motivational relevance and the other motivational congruence (Smith & Lazarus, 1993). A transaction with the environment would be regarded as stressful and would lead to negative emotions if it is of personal relevance to the individual i.e. motivationally relevant and at the same time is inconsistent with the individual's aims or goals i.e. motivationally incongruent. On the other hand, an interaction would be considered beneficial or positive if it is in line with an individual's desires and is therefore both motivationally relevant and congruent and not stressful (Folkman & Lazarus, 1988), hence; this kind of appraisal is most likely to yield positive emotion. For example, the primary appraisal of the diagnosis of a child with developmental disability may lead to feelings of potential threat to the well-being of the parents as this appraisal of diagnosis will be both motivationally relevant and incongruent at the same time for the parents.

Another primary appraisal for the same transaction may be of it being perceived as threatening which would result an individual to employ secondary appraisal to determine the ways in which the potential harm can be prevented and well-being promoted. Secondary appraisal therefore is the evaluation of how likely would an individual will be able to cope with a potential threatening situation. Secondary appraisal can be classified into different components which influence the type of coping mechanisms and the specific emotions experienced (Folkman et al., 1986; Smith & Lazarus, 1993). These consist of accountability or determining who is responsible for the situation; weighing the adaptability for problem-focused, emotion-focused or meaning focused coping strategies; and, future expectancy to determine how likely the situation is to change in the future. In such scenarios, primary and secondary appraisals merge to determine whether the transaction is primarily threatening with a possibility of loss or harm; or challenging with a possibility of gaining mastery or benefit (Folkman et al., 1986).

Another form of appraisal is ‘reappraisal’, which refers to a changed appraisal based on new information from the environment or an individual’s own reactions (Lazarus & Folkman, 1984). As the name suggests, reappraisal appraises an earlier appraisal of the same encounter but modifies the initial appraisal. The difference between primary appraisal and reappraisal is that reappraisal follows an earlier cognitive evaluation. Unexpected differences in control over an unfolding series of events require individuals to reassess the events significance resulting in reappraisal (Lazarus & Folkman, 1988). Using primary and secondary appraisals and reappraisals people continuously evaluate a stressful situation and may employ various coping strategies based on the situation as it unfolds.

According to the transactional model, the coping techniques employed by individuals would be greatly influenced by the individual’s cognitive appraisal of the event, the strategies available at the given point in time and their perceived effectiveness; therefore, different individuals would use different coping strategies based on their personal appraisals (Folkman & Lazarus, 1988). To summarise, primary appraisals evaluate the perceived control over a situation; secondary appraisals guide the use of coping strategies; and the effectiveness of the coping strategies leads to further reappraisal.

In applying transactional theory to determine the stress and coping strategies used by parents of children with various developmental disabilities, it is clear that this situation would be appraised as personally relevant to all parents. It is also expected that having a child diagnosed with a developmental disability would be motivationally incongruent with the parents’ desires and therefore cause stress. However, the level of this stress, kind of appraisals and the use of coping resources would vary considerably depending upon various factors such as the parent’s individual beliefs and outlook towards the child’s disability, values, personal control over the situation and sense of stability amongst others. If properly utilised effective coping resources and strategies may help the parents to moderate vulnerability to the effects of this stress (Armstrong, Lefcovitch & Ungar, 2005; Park, Folkman & Bostrom, 2001) and also regulate emotions (Folkman & Moskowitz, 2004; Lazarus, 1993).

Coping

Lazarus & Folkman (1984) defined coping as an individual's response of "constantly changing cognitive and/or behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, pp141). Their definition of coping suggests that coping is (i) process oriented rather than trait based, and (ii) it should not be likened with psychosocial outcomes as it focuses on the attempts and efforts to master a given situation. According to Livneh and Martz (2007), coping efforts act as moderators of the psychosocial outcomes and mediators between the crisis and the between the existing crises and the psychosocial outcome (e.g. reducing psychological stress) they are desired to influence. These efforts directed at external stressors and internal demands, encompass a range of cognitive, emotional and behavioural strategies aiming to resolve an unpleasant situation (Lazarus, 1993).

Lazarus and Folkman (1984) define coping as an ongoing dynamic process that changes constantly in relation to the changing demands of the stressful situation, suggesting that coping is process oriented. From a process standpoint Lazarus (1993), explains that coping depends upon the context or appraisal of the stressful situation which is likely to change over time because of what is attended to, and the perception of threats change at different points in time. The principle therefore of the process of coping varies with the diverse adaptational significance and requirements of dealing with potential threats (Lazarus, 1993).Therefore, a narrow definition of the context would lead to a better linkage between the coping thought and a contextual demand.

Also, within this approach Lazarus and Folkman (1984) introduce the importance of “change” in the relational meaning or coping thoughts as a stressful event unfolds, making coping a “shifting process” (p.142) in which individuals may rely initially more on one form of coping but may adapt defensive strategies gradually as the person-environment relationship unfolds or changes. According to this approach, coping is defined by the person’s attempt to manage the environment and not by whether or not that attempt was successful. Coping hence should be studied in context of what a person” actually think or does” (p.142) as opposed to what he or she should do. Therefore, being an ongoing process, coping may constantly evolve; the following section will discuss in detail the various stages of the coping process.

Stages in the coping process:

As coping is a constantly changing effort it is important to note that changes in coping behaviours are often conceptualised as occurring in stages; the three stages usually defined in terms of cognitive appraisal are: (i) anticipatory or warning; (ii) impact or confrontation; and (iii) post impact or post confrontation (Lazarus & Folkman, 2001), these are elaborated below:

The first stage of ‘anticipation’ is when the event has not yet occurred and is being anticipated. For example, for a child with a developmental disability to go through the puberty is an anticipated stage for the parents; therefore the paramount issue to be appraised in light of the child’s diagnosis i.e. primary appraisal is whether this event will happen, when it will happen and what will happen hence. The secondary appraisal may lead to evaluations such as to how well the child may be able deal with this, or, what extent and how can the parent manage this threat (the transition); or can there be steps taken to minimize the potential damage (to the well-being of the child and parent). During the process of anticipation, these evaluations or thoughts can affect a parent's stress reactions and coping behaviours and they may use strategies such as avoiding thoughts about imminent threat, denying its implications or gathering information to find something relevant to help them to cope.

The second stage is that of the 'impact' when issues concerning the sense of control do not remain as relevant because the potentially harmful event has either already begun or ended. As the anticipated situation unfolds, the person starts to make inferences as to whether the situation is as bad as or far worse than what was anticipated in the previous stage. For example, a child with a developmental disability may pass through this period of puberty with either much ease or in a much worse manner than the parents initially anticipated; this difference in the anticipation and actual control over the event may lead to assessing the importance or reappraising the situation once again.

The last stage is the 'post impact' which is a continuation of the cognitive processes that began during the impact period in addition to the new considerations that emerge based on the significance of what has happened. For example, will the experience of going through puberty impose new threats or challenges to the child's well-being or will the child return to the status quo ante?

Even after its end, a stressful encounter brings in a new set of anticipatory processes, and an individual develops a set of appraisal and coping processes addressed not only to the present and the past but also to the future. Coping therefore is a reciprocal process, which involves a continuous appraisal of the person-environment relationship using various coping strategies.

The Functions of Coping

Lazarus and Folkman (1980; 1984), condensed this division of coping into two overarching functional categories that of- regulating or managing stressful emotions or emotional distress (emotion-focused coping) and altering the troubled person-environment relation causing the distress (problem-focused coping). The process of coping therefore serves two functions: one of which is to change the troubled person-environment relationship, by either acting on the environment or oneself i.e. problem-focused coping. The second being, emotion focused coping which aims to change either the relational meaning of what is happening but not the context (e.g. denial) or the way the stressful relationship with the environment is attended to (e.g. avoidance) (Lazarus,1993).

By definition, problem focused coping is goal-directed. Problem focused coping involves cognitive and behavioural problems solving strategies such as gathering information, planning, resolving conflicts to manage or alter a stressful situation (Lazarus & Folkman, 1984). Problem-focused coping strategies are further divided into two domains: confrontive and planful problem solving which aim at trying to change the originator or the cause of the stress. On the other hand, emotion-focused coping involves behavioural and cognitive efforts to manage or reduce emotional distress not focussing directly on solving the problem. Emotion-focused coping aims to reduce the levels of distress by using techniques such as denial, acceptance, ruminating, acceptance and interpreting the problem in a positive light (Folkman & Lazarus, 1988).

Support for the role of cognitive appraisals from the empirical literature:

As discussed above, according to the transactional model the coping techniques employed by individuals are influenced by their cognitive appraisal of the event, the strategies available at that given point in time and their perceived effectiveness. Therefore, different individuals would use different coping strategies based on their appraisals (Folkman & Lazarus, 1988). The use of coping strategies appear to differ for events appraised as controllable versus uncontrollable (Folkman & Lazarus, 1980; Parkes, 1984; Stone & Neale, 1984). Essex, Seltzer and Krauss (1999), for example, concluded from their study of coping effectiveness among parents of adults with mental retardation that there was a greater incidence of problem-focused coping within this group which led to a negative impact of caregiver stress on the mother's well-being. In contrast, Miller, Gordon, Daniele and Diller (1992), reported that mothers of children with disabilities found emotion-focused coping led to increased stress. Smith et al., (2008), studied the coping style of mothers of children with autism and found that problem-focused strategies correlated with greater well-being in the mothers as compared to the use of emotion-focused coping strategies. However, in terms of adjustment, whether to change circumstances (problem focused) or emotions (emotion focused) people are actively making an effort to deal with the stressor. For example, people who approach the stressor either through problem or emotion focused coping may have better outcomes in comparison to people who try to avoid the stressor completely (Solberg Nes, Segerstrom, 2008). It is therefore important to acknowledge this process of coping and understand that it may intervene differently for different individuals in different stressful situations. However, studies aiming to train clinical populations in coping effectively conclude that the goodness of fit between a desired coping strategy and the changeability of a situation is an important determinant of the degree of psychological distress experienced during a stressful situation (e.g. Pollard & Kennedy, 2003; Chesney et al., 2003). If an individual continues to use a certain coping technique inappropriate to a specific situation, it may likely have an adverse effect on the individual’s well-being in the long term (Folkman & Lazarus, 1988). It is therefore important that individuals can distinguish which coping strategy is effective for them to reduce stress when faced with stressful situations.

The transactional model’s concepts of coping are widely used in areas of disability research (Peer, 2011). Glidden and Natcher (2009), studied the use of coping strategies with sixty eight married couples who had children with various developmental disabilities. The researchers hypothesised that early use of problem-focused coping strategies would predict a greater sense of parental well-being. As hypothesised the results of the study indicated that problem-focused strategies were highly correlated to the subjective well-being of the parents and resulted in lower levels of depression amongst parents. However, it can be argued that due to the complex nature of the stressor, the long-term nature of diagnosis and the uncertain nature of achieving developmental milestones, both problem-focused and emotion-focused coping strategies remain effective and maybe used interchangeably by parents depending upon the nature of a specific situation.

Also, in relevance to this thesis is Aldwin and Brustrom’s (1997) review of coping with chronic illnesses, which suggests that the use and frequency of coping strategies employed by an individual sometimes decrease over time, as individuals develop routines to deal with chronic stressors to minimize the potential stress. For example, for chronic illnesses such as asthma, developing a routine for diet, exercise and medications may help to reduce flare-ups and stress related to these conditions (Aldwin, 2007). Therefore, fewer numbers of coping strategies may be employed as a result of fewer crises to deal with over time and also identification of which particular strategies are more effective than the others. Due to the same reason, the parents of children with developmental disabilities may gradually reduce the number of coping strategies they employ over time with constant appraisal of the situation and after identifying which strategies are most effective in addressing particular stressors in their situation.

Critique of transactional model of stress and coping

Although, the problem and emotion focused dimensions have been supported by various researchers in the field, there is disagreement as to which coping strategies should constitute these realms (e.g. Billings & Moos, 1981; Carver, Scheier, & Weintraub, 1989; Coyne, Aldwin, & Lazarus, 1981; McRae, 1984; Pearlin & Schooler, 1978). Cooper et al. (2001), and Cox and Ferguson (1991), have stated that despite the widespread use of the term “coping” there are difficulties surrounding its definition, as it can be seen as a process, a behaviour, as a stable trait, or as situation specific. Briner, Harris and Daniels (2004), have suggested that the conception of appraisal is too simplistic and does not include individuals’ histories, and anticipated futures. Cox (1987), also states that the processes of stress and coping may not be as rational as presented in transactional theories. Critics have also argued that this division of coping is rather limiting and not stable empirically (Carver et al., 1989). Studies show that this division constitutes of much more than two constructs (Scheier, Weintraub, & Carver, 1986). Scheier et al., (1986), argue that emotion focused coping responses often diverge fundamentally and are per contra correlated, to illustrate, some emotion-focused responses involve avoidance or denial, while others may constitute seeking support or finding a positive meaning. Carver et al., (1989), hence reprove by arguing that such responses classified as emotion focused (e.g. denial and positive reinterpretation) are distinctly different and thus may have very different significance for an individual's success in coping. Taking the debate further, Segerstrom & Connor (2012), argue that whether people use problem or emotion focused coping, it is more important to acknowledge their use of coping i.e. approach or avoidance coping. So according to them, people who are trying to address the stressor by initiating a coping response have better outcomes than the ones who try to avoid addressing this issue of stress (Solberg, Nes, & Segerstrom, 2008).

As a consequence of this argument in the study of coping, additional dimensions such as avoidance coping (Chung et al,. 2001; Billing & Moos, 1981) or meaning focused coping (Gillies & Neimeyer, 2006; Park & Folkman, 1997; Segerstrom, Stanton, Alden, & Shortridge, 2003) have been added to this broad division. According to Lazaarus and Folkman (1984), the process of coping yields to an outcome, which can be either favourable or unfavourable; throughout this process of appraisal, coping and outcome, emotion, is generated concurrently. In the case of a favourable outcome the coping process leads to a positive emotion because of resolution, on the other hand, in the case of an unfavourable or no resolution, for example, in the case of having a chronic condition or a developmental disability the coping process may lead to distress or the need for additional coping. Hence, Folkman (1997) suggested that if the use of the appraisal- emotion-coping-reappraisal process leads to an unfavourable outcome, the need to try again to deal with the situation triggers 'meaning-focused coping'.

Meaning focused coping is a form of appraisal based coping through which an individual draws on his or her beliefs, values, and existential goals to motivate and sustain coping and wellbeing during a stressful time (Park & Folkman, 1997). This form of coping leads to the generation of positive emotions and new appraisals thereby influencing the stress process by restoring coping resources and advancing motivation required to sustain problem-focused coping over time. Folkman & Moskowitz (2007) identified the following categories of meaning focused coping: benefit finding, benefit reminding, adaptive goal processes, reordering priorities, and infusing ordinary events with positive meaning. In the case of dealing with the chronic stress of having a child diagnosed with a long term health condition and atypical development the possibilities for a major change to happen in objective characteristics of the situation concerned are very few, in such scenarios, meaning-focused coping may serve as a driving force for positive emotions in parents dealing with this long term dilemma.

Consistent with the Folkman and Lazarus (1980) classification of the functions of coping, Billings and Moos (1981) proposed a three-factor coping model consisting of Active Behavioural coping (problem focused), Avoidance (emotion focused) and Active cognitive coping (emotion focused). The functions of coping according to this model are to change the situation (active behavioural), change the meaning of the situation (active cognitive) or to make efforts to control the stress itself. Similarly, coping has also been conceptualized into (i) task-oriented coping, (ii) emotion-oriented coping and (iii) avoidant-oriented coping by Endler and Parker (1990).

Carver et al., (1989), on the other hand, have also proposed a model of coping, dividing it based on the functional properties of coping but not being subsumed into two or three distinct categories. These divisions amongst the researchers within the coping fraternity may be attributed to an important caveat which is the fluidity of the coping process and the circumstances it occurs in, making it rather a difficult process to conceptualize (Segerstrom & Connor, 2012). Another major issue concerning coping is the identification of the best model of coping. There are studies that offer a mediational perspective to coping wherein, a stressor or its appraisal affects an individual to initiate coping. However, some studies may consider a moderator model where the relationship between the stressor or stress appraisal is affected by coping. Coping may intervene between the stress appraisal and stress albeit in different ways (Arigo & Smyth, 2012).

A somewhat different classification of coping has been proposed by Skinner et al., (2003), which categorises coping in a hierarchical model. Skinner and colleagues argue that due to the nature of coping it cannot be unequivocally observed, and that all coping responses are calibrated to specific demands and are influenced by the resources and contexts in which they unfold, and therefore may virtually be infinite in their variety. In order to understand this rather complex structure of coping the authors point out that the categories of coping must be organized with respect to their functions, and propose that a hierarchical view of coping may provide a useful framework for this task (Skinner et al., 2003). This division of coping consists of the highest order (superordinate) categories, followed by mid-level coping strategies, which is followed by the lowest order or subordinate categories made up of situation specific responses to the stress stimuli.

Expanding this model further, Skinner and Zimmer-Gembeck (2016), differentiated between the lower-order ways of coping and the higher order dimensions and categories of coping. They collated a set of lower-order categories (e.g., support-seeking, denial, passivity) which could reliably classify instances of coping (observations or items) into conceptually clear, mutually exclusive, and exhaustive categories. They suggested that, these lower-order categories must also themselves be classified into higher order categories (e.g., accommodation, emotion-focused coping) according to their adaptive functions. The authors generated over 400 different labels for ways of coping (e.g. support-seeking, worry/rumination, distraction, cognitive, information-seeking, denial, decision-making, helplessness, blaming others) which were derived for the most part from individual items (or instances). The exhaustive list of the 400 ways of coping thus generated represents the state of the overall field in terms of coping categories. These categories are good descriptors of instances of coping and cover much of the territory of action options during stressful transactions. However, it can be argued that this list provides little guidance in how to go about creating a comprehensive measure for any specific study. Even though there is a large number of coping categories in this list, it needs to be noted that the categories are connected to each other in many different ways; such as instrumental social support, help-seeking, and seeking advice or problem-solving, information-seeking, and planning. Whereas, other categories appear stark opposites, such as help-seeking and social isolation. Skinner and Zimmer-Gembeck (2016) advocate that it is important to identify a set of higher-order categories that reflect and order the fundamental distinctions underlying lower-order categories of coping. They argued that higher-order core categories of coping that are based on adaptive functions provide hierarchical organization for the lower-order ways of coping. These high order categories have been created by a rational classification of lower order categories to induce higher order categories, combined with theoretical analysis of functions of coping to deduce higher order categories or dimensions.

Skinner and Zimmer-Gembeck (2016) argue that single functions (e.g., problem vs. emotion focused) are not good action categories because any given way of coping is likely to serve many functions. Unlike Lazarus and Folkman (1985), Skinner (2008) argued that topological distinctions (e.g., approach vs. avoidance, active vs. passive, or cognitive vs. behavioral) are not good action categories, because all ways of coping are multidimensional. For higher order categories of coping, they recommend that the three most common distinctions (problem- vs. emotion-focused, approach vs. avoidance, and cognitive vs. behavioral) no longer be used. Instead, the authors recommend hierarchical systems of action types (e.g., proximity seeking, accommodation) as the best higher order categories. Similarly, Skinner, Edge, Altman and Sherwood (2003), argue that problem-focused and emotion-focused coping are not useful as higher order coping categories, they suggest that the categorisation of problem-focused and emotion-focused coping is not conceptually clear, mutually exclusive, or exhaustive. They further the debate by exemplifying that emotion-focused coping lacks clarity as when used as a higher order category it is unclear as to which lower order categories it contains. They reiterate their claim by an example where active attempts to calm oneself are considered emotion focused, as are uncontrolled venting and panics. Second, the authors claim that the division of problem focused versus emotion focused is not mutually exclusive, they argue that relatively most ways of coping serve both functions and therefore can fit into both problem focused and emotion focused categories. They elaborate this by giving the example, of making a plan, which may not only lead to solving a problem but also towards calming emotion. Their third argument against the problem focused and emotion focused divide is that these two categories are not exhaustive with respect to lower order categories of coping, as certain ways of coping fall outside both these measures. They illustrate by suggesting that seeking social support for example is focused neither on the problem nor on emotion but instead on the self. Skinner, Edge, Altman and Sherwood (2003), conclude that the emotion focused, problem focused, and appraisal-focused categories are not mutually exclusive and therefore, this distinction should not serve as a structure for classifying ways of coping. Lazarus (1996) agrees with Skinner, Edge, Altman and Sherwood (2003), and recommends that "distinguishing between the two functions, but treating them as if they were distinctive types of coping actions, has led to an over simple conception of the way coping works and is measured in much research" (p. 292).

Resource –based models of stress and coping

The coping process is influenced by various factors such as the characteristics of the individual, their personality and environmental factors, and therefore is likely to have both stable and variable aspects (Folkman & Greer, 2000). As discussed, various personal characteristics and demographic variables influence people's primary and secondary appraisals of the stressor, which in turn influence the stress with which they feel they must cope (Folkman et al., 1986). The resources for coping available to an individual can be divided into external and internal resources (Hobfoll, 1998; Moos & Schaefaer, 1993). External sources of coping constitute of environmental factors, for example, social support, financial resources and time. These sources may act as buffers to maintain the coping process. In disability studies, environmental factors such as financial resources, the prevailing systems of education, health care and social services, assistive devices or technology, and the community (Infeld & Whitelaw, 2002; Vincent et al., 2007) may play a very important role in initiating and maintain the process of coping. Studies have also acknowledged that an important external source in coping is social support which may act as a significant discriminator for the severity of stress (Chokkanathan2009; Strating, Suurmeijer, & van Shcuur, 2006).

Internal sources constitute of particular personal traits or dispositions that may predict better or worse adaptation towards a stressor for example, hardiness, optimism, self-efficacy, sense of coherence as opposed to pessimism, neurotocism or low self-worth. An individual's coping response may be highly influenced by their internal characteristics, especially personality traits (Costa et al., 1996; Watson, David, & Suls, 1999). Personality can be a significant long-term antecedent of coping (Vollrath, Torgersen & Alnaes, 1995). According to Lazarus and Folkman (1984), personality or dispositional variables can influence the appraisal of a stressor and can be related to a sense of personal control over outcomes of importance, such as concepts of dispositional optimism (Scheier and Carver, 1985), mastery (Pearlin et al., 1981) or hardiness (Ouellette, 1993). For example, personality traits such as optimism, sense of coherence have been proven to confer a coping advantage not only when something can be done to deal with the stressful event but also when the event is something that must be gotten used to. Dispositional optimism refers to generalized outcome expectancies of positive outcomes (Carver, Scheirer, & Segerstrom, 2010; Rasmussen, Scheier, & Greenhouse, 2009; Scheier & Carver, 1985); hence, higher dispositional optimism may lead to greater recognition and expectancies that an event will be favourable in some way or the other. There is an established link between dispositional optimism in parents and better psychological adjustments, as optimism may affect how a parent appraises their environment and how they behave thereby influencing their coping behaviours towards their child's disability (de Schipper, Riksen-Walraven, Geurts, and Derksen, 2008; Kayfitz, Gragg, and Orr 2010; Walsh, 2003). Studies in the field of childhood disability suggest that optimism moderates depression and marital adjustment in parents of children with developmental disabilities (Baker, Blacher, & Olsson, 2005). The authors conducted a study which investigated the impact of optimism on measures of well-being for parents of preschool children with and without developmental delays. Their study explored the moderating impact of optimism and the correlations between child behaviour problems and parental wellbeing. Optimism was found to moderate the relationship between behaviour problems and parental wellbeing, especially for mothers. On the other end of this personality continuum is neuroticism (Eysenck & Eysenck, 1975), which refers to negative traits, negative affectivity as well as associated emotions and states such as sadness, anger (Watson & Clark,1984).

Moos, & Holahan (2003), argue that the exclusive use of a dispositional view in the coping literature provides rather limited information about the coping choices which individuals use in specific stressful contexts. Similarly, Carver, Scheier, and Weintraub, (1989), argue that there is evidence to suggest that general coping styles and dispositions do not strongly transfer to the actual coping efforts individuals use to manage specific stressful circumstances. However, studies suggest that both coping responses and coping dispositions put together can explain significant amounts of variance in coping (Bouchard, 2003; Moos & Holahan, 2003; Penley and Tomaka, 2002; Suls, David, and Harvey, 1996).

Coping Effectiveness:

A key hypothesis of the transactional approach is that a particular strategy or style of coping cannot be defined as effective or ineffective independent of the context in which it is used. Therefore, coping effectiveness is dependent on the match or goodness of fit between coping efforts and other variables in the stress and coping process, Coping effectiveness hence is dependent on the "match" or "goodness of fit" between coping efforts and other variables in the stress and coping process. These include an individual's values, beliefs, and commitments (Folkman, Schaefer, & Lazarus, 1979), preferred coping style (Miller, Gordon, Daniele & Diller,1992) and the use of coping strategies which differ for events appraised as controllable versus uncontrollable (Folkman & Lazarus, 1980; Parkes, 1984; Stone & Neale, 1984).

Based on research findings (Carver et al., 1993; Lazarus, 1993; Moos, 1984) coping strategies may vary both within (i.e. they change over time) and between (i.e. they are person specific) individuals with the aim of potentially managing the effects of both long term and short term stressors. A complex interplay of factors contribute towards effectively adapting to a stressful situation, such as the nature of the event itself, the individual's cognitive appraisal of this event, personal and social coping resources available to the individual, and the actual coping strategies that they employ (Lazarus & Folkman, 1984). Therefore, determined by the nature of a stressor (short term, long term, chronic), an individual may require the initiation of a versatile repertoire of coping strategies which may be differentially effective.

According to the transactional model, during a stressful encounter people are amenable to change to and from between problem-focused and emotion focused coping strategies (Folkman & Lazarus, 1988). Maladaptive coping may occur when people respond to changeable stressors with emotion-focused coping strategies or to unchangeable stressors with problem-focused coping strategies (Vitalianio et al., 1990). Based on the transactional theory and evidence from studies of coping, an individual who is caring for a child with a developmental disability will be going through a more or less chronic stress and therefore might engage in problem-focused or emotion-focused coping techniques on most occasions during the course of providing care for their child based on their appraisal of the stressful event. Although both problem-focused and emotion-focused coping are used for overcoming controllable and uncontrollable events, studies indicate that coping efforts intended to alter the source of stress by acting on it directly (problem-focused coping) tend to be used more with events appraised as controllable, while palliative coping strategies to moderate emotional reactions (emotion-focused coping) are used more with events perceived as beyond personal control (eg. Dabrowska, & Pisula, 2010; Hastings, 2002; Miller, Gordon, Daniele, & Diller, 1992; Stone & Neale, 1984). This pattern supports a goodness of fit hypothesis, since individuals appear to attempt to change those stressors that they believe they can control and adapt to those they believe they cannot change.

It is also plausible that at certain times though one form of coping may be deemed better than the other, for example, when waiting for diagnosis or medical test results etc. people may employ only emotion focused coping techniques such as avoidance coping to combat the uncertainty of the situation (Phelps, Bennett, Iredale, Anstey, & Gray, 2006). This form of coping involves cognitive and behavioural efforts oriented toward denying, minimizing, or otherwise avoiding dealing directly with stressful demands. Avoidance coping includes the use of strategies such as distraction, denial, repression or suppression and the effectiveness and adaptational value of using avoidance coping has been a topic of much debate and research (e.g. Lazarus, 1983; Suls & Fletcher, 1985). Rationale from this debate generally suggests that there are specific situations where avoidant coping maybe appropriate and effective, for example, in an early stage of a stressful encounter when an individual may lack the capacity to engage in problem-focused coping (Lazarus, 1983).

A meta analyses conducted by Suls & Fletcher (1985) suggested that avoidance was associated with more positive adaptation in the short-run; in contrast, though predictably, avoidant coping was closely linked to distress and depression in the long run in various studies (Cronkite & Moos, 1995; Penley, Tomaka, & Wiebe, 2002). Reliance on avoidance coping is likely to generate a broad range of stressors in particular scenarios, where the stressors may be deemed chronic, such as a long term illness. Hastings et al., (2005), suggest on the basis of their study that that avoidance coping appears to be maladaptive (associated with more stress and mental health problems), and positive approaches to coping may be adaptive in parents with children who are diagnosed with autism (associated with less stress and fewer mental health problems). The authors suggested, interventions with parents therefore, might, on the basis of these findings, focus on reducing parents' use of avoidant coping strategies and increasing their use of positive coping, perhaps by enhancing their positive perceptions of raising a child with autism. In their study which aimed to explore the mediating effects of coping strategies and cognitive appraisals Miller et al., (1992), concluded that emotion-focused coping style which included techniques such as distancing and escape avoidance was related to increased psychological distress in mothers. These and other studies indicate that broader theory in coping literature suggests that coping is situation or context-dependent (Carver et al., 1989; Lazarus & Folkman, 1984). Therefore, both the nature of the stress and the interaction between stressors and the environment, for example, limitations imposed on the availability of certain coping strategies owing to limited social support networks for parents of children with developmental disabilities, should affect the development of coping efforts. From the above discussion it can be concluded that, regardless of their level of effectiveness, the strategies of coping can be regarded as an important mediating factor between a stressful encounter and the ultimate psychosocial outcome. Thus, coping may have an adaptational significance irrespective of the outcome. The following section highlights this facet of coping.

Positive affect and coping

During the late nineties, Folkman (1997) proposed a modification to the Transactional Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) in order to take positive psychological states involved in stress and coping into account. According to Folkman & Moskowitz (2000), most models of stress and coping do not highlight the adaptational significance of the types of coping processes which people use to initiate or sustain positive affect whilst dealing with a rather enduring stressful situation. They argue that, positive affect can occur simultaneously with distress during a given period; and has an important adaptational significance of its own. Finding positive meaning in a stressful situation can be considered an appraisal process, where an individual cognitively reframes a challenge in an attempt to alter its emotional impact (Folkman

& Moskowitz, 2000). In the case of caring for a child with a developmental disability, the parent is likely enduring a stressful situation and thus may initiate positive affect in order to adapt to this long-term stressor by appraising it positively or cognitively reframing it to achieve an altered emotional impact from the same situation. Fredrickson (2001), argues that the experience of positive affect prompts individuals to engage in their surroundings and to participate in activities which may be adaptive for them. Increasing empirical evidence shows that positive affect occurs during periods of chronic stress (e.g. Fredrickson, 2001; Patterson, 2002a; Pearlin, 1991; Viney 1986); this positive affect can have significant adaptive functions both under normal and stressful conditions (Folkman & Moskowitz, 2000). Fredrickson (1998), based on an extensive review, suggested that positive emotions in individuals in the midst of chronically stressful situations yield to building better social, intellectual and physical resources.

Lazarus, Kanner and Folkman (1980), hypothesized that under stressful conditions, negative emotions are predominant, but positive emotions at the time are able to provide a much needed psychological break in order to support continued coping efforts made by the individual and to replenish the resources that have been depleted by stress. Studies also indicate that positive affect may also help to counter against the adverse physiological effects of stress (Gross & Munoz, 1995; Moskowitz, Acree & Folkman, 1998). For example, in a chronically stressful situation, positive affect may help prevent clinical depression as positive regulatory experiences may compensate and regulate emotions time to time. Positive affect has also been shown to promote creativity and flexibility in thinking and problem-solving (e.g. Isen & Daubman, 1984; Isen, Daubman, & Nowicki,1987).

According to Folkman & Moskowitz (2000), three kinds of coping processes generate positive affect: (i) positive appraisal- i.e. the cognitive strategies used to reframe a particular situation to see it in a positive light such as benefit finding to be able to appraise a situation in a positive way. (ii) goal-directed problem focused coping- i.e. efforts aimed at managing the problem that is causing distress such as gathering relevant information, planning, acquiring resources, and performing task-oriented actions (Lazarus & Folkman, 1984). For instance, problem focused coping may allow an individual to focus attention on set goals, feel in control of the situation and enact caregiving responsibilities resulting in positive affect. (iii) infusion of ordinary events with positive meaning- Folkman & Moskowitz (2000), posit that the occurrence of a negative event motivates an individual to create or interpret an otherwise ordinary event as positive in order to mitigate the negative affective consequences of the negative event. In their study of stress and coping of caregivers of people with AIDS, 99.5% of participants reported a positive event which they noticed during the day which made them feel good and was meaningful to them implying that the participants were clearly noting, remembering and recalling positive events or infusing positive meanings to ordinary events in the midst of their distress (Folkman, 1997a). Lazarus (1999, 2006) argues that coping is a powerful mediator of the emotional outcome resulting from a stressful environmental transaction and it influences the relationship between the person and the environment and can therefore influence how the person feels as a result of this transaction.

Family specific models of stress and coping

In close affinity to Lazarus and Folkman's transactional model of stress and coping, family stress and coping was also studied in-depth by Hill (1958) and McCubin and Patterson (1983) who proposed the ABCX Formula and the Double ABCX model of family stress respectively which is discussed in the following section. The Double ABCX Model of Family Stress (McCubbin & Patterson, 1983) is similar to Lazarus' Transactional Model of stress and coping in the way it incorporates the concepts of emotion-focused and problem-focused coping, however this model ties these concepts into specifically explaining the family stress process. Furthermore, concepts or issues that are central to the ABCX theory, such as demand-resource balance, definition of the situation, and variables influencing regenerative power, are included in the transactional model, but without the trappings of a complex, highly-structured framework (Smith, 1984).

The ABC-X and the Double ABC-X Model of Family Stress

It is being recognised that despite having a child with severe intellectual disabilities and behaviour problems, some families are resilient and adapt well (Gerstein et al., 2009). Recent studies have shown that although some families are at risk for having numerous difficulties (Gray, 2003; Seltzer et al., 2011; Seltzer et al., 2004) many families positively cope and adapt to the stress of parenting a child with developmental disabilities (Scorgie & Sobsey, 2000). A large body of research has shown that family outcomes can vary from healthy adaptation to maladaptation because of changing family responses over time (Donovan, 1988). Current literature has therefore moved away from the single cause and effect relationship between parental stress and pathology and has emphasized the successful adaptation of families. There are numerous factors which have been demonstrated significantly related to adaptation processes of families such as social support, sense of coherence (Antonovsky, 1987), characteristics of the child; and family quality of life

(Pozo, Sarria & Brioso, 2014) amongst others. Given that research has clearly indicated the potential for stress in parents of children with developmental disabilities and also the fact that a continuous effort for adaptation is being made by these families to maintain a state of balance, it is important to examine the psychological, intra-familial and social variables simultaneously to study the adaptation which mediates the stress in these families. The theoretical framework of the double ABCX model allows studying these variables concurrently. The transactional model of stress and coping emphasises that the selection of coping strategies is determined not only by stable characteristics of the individual but also by situational characteristics (Lazarus and Folkman 1984) and the ABCX and the Double ABCX model effectively study these characteristics.

The ABCX and the Double ABCX model of family stress incorporate a normative family life cycle perspective, which can be adapted to examine stress, coping and adaptation of families who are caring for a child with a developmental disability. McCubbin & Patterson (1983) developed this model of family stress which aims to explain the process of stress and coping at a familial level to provide an understanding of how families change, adapt, approach and manage stressful situations. This model is particularly relevant to this study as it has its roots embedded into identifying how different families approach and deal with having a child diagnosed with developmental disabilities as it aims to explain how some families are able to cope with this situation rather resiliently whilst others become too subjugated. The multivariate approach of this model has been considered relevant in examining the psychological, intra-familial and social variables associated with stress and coping mechanisms at a familial level.

The ABC-X Formula

An influential model that has been used to understand parental stress is the ABC-X model proposed by Hill in 1958. Reuben Hill (1958), is referred to as the 'father of family stress models' (Boss, 2002), due to his contribution of this formula, which is the basis of various family stress models and aims at explaining "the crisis-proneness and freedom from crisis among families" (p.143).

Hill defines stress as "A state which arises from an actual or perceived demand capability imbalance in the family's functioning and which is characterized by a multidimensional demand for adjustment or adaptive behaviour" (McCubbin and Patterson, 1983. pg. 9). Crisis results when a family is unable to regain a state of homeostasis and there is constant strain and pressure upon the family to change their structure and pattern of interaction. This crisis therefore arises when a family perceive stress as undesirable or unpleasant. According to this model, an interaction within the "A", "B", and "C" factors results in stress for the family unit: A (the stressor) ... interacting with B (the crisis meeting resources of the family) ... interacting with C (the evaluation of the stressor by the family) ... produce X (the crisis)." (pg.8).

'A': refers to the crisis-precipitating stressor or event, Hill (1958), used this term to imply "a situation for which the family has had little or no prior preparation and must therefore be viewed as problematic" (p.139). Hill (1958) further described a hardship as complications of a stressor that would demand various competencies (resources) from the family unit specifically associated with the stressor event. Strain is caused due to the stressor and the resulting hardship upon the family and requires conscious effort by the family to be managed. In the present study, the condition of the child is the stressor while the time and effort to manage caring which may involve changing in work and social schedules for example would be the resulting hardships that need to be managed by the family.

‘B’: is the family’s crisis-meeting resources; the ABCX formula suggests that the stressor and the resulting hardship interact with “B” which is the family’s crisis meeting resources, and the well-being of a family may depend to a large degree over the adequacy or inadequacy of these resources available for them. For example, the degree family adaptability can potentially prevent or minimize a disruption within the family unit.

‘C’: Within Hill’s model factor “C” can be understood as the subjective value or meaning given to the stressor. He suggested that if a stressor event is defined as challenging it would lead to more proneness to crisis; for example, while some families may regard the stressor as a welcome challenge, others may regard it as an uncontrollable situation with an impossibility to change, rendering it highly stressful.

‘X’: is the family crisis which as Hill (1958), termed would result in “slowed up affectional and emotion-satisfying performances” (p.146). For example, to manage the caring situation with available resources may lead to stress, however if the parents determine that a change or adjustment is not required this would circumvent any experience of distress or crisis.

To summarise the ABCX Formula, A, the stressor interacting with B, the family’s crisis meeting resources interacting with C, the definition the family attributes to the event produces X which is the crisis. As in the transactional model, Lazarus' concept of primary and secondary appraisal is evident in the "A", "B" and "C" factors as in both models the situation or environment is appraised by the individual and thus attributed with a positive or negative meaning and an evaluation of resources is performed to determine if the situation can be managed successfully or not.

McCubbin (1979) expanded the original ABCX model in order to assess post-crisis behaviour, and include coping strategies, external resources and the accumulation of various life stressors; thus, McCubbin and Patterson (1983), developed the Double ABC-X model of stress and coping. In this model, a parent's ability to cope with a stressful situation is determined by the interaction of the stressor event and subsequent life stressors, family resources, parental perceptions and coping strategies; and the outcome of this interaction is the level of family adaptation which may vary from severe stress to successful adaptation (Jones & Passey, 2005).

Double ABCX Model of Family Stress

The Double ABCX model of family stress has been adapted from the above mentioned Hill's original 'ABCX Family Model' and was developed by McCubbin & Patterson (1983). It aims to explain the process of stress and coping at a familial level to provide how families change, adapt, approach and manage stressful situations. This model is particularly relevant to this thesis as it may aid in understanding and identifying how different families approach and deal with having a child diagnosed with developmental disabilities; and explain how some families cope with this situation rather resiliently whilst others become too overwhelmed.

For a family with a child who has a developmental disability to manage a situation with available resources may lead to distress because of the level of adjustment or adaptation required. Often families deal with several stressors impacting them at the same time, in their Double ABCX model; McCubin and Patterson refer to this pile-up nature of stressors as the “aA” factor.

Aa: (Pileup) The authors claim that five different kind of stressors lead to the piling up effect during a period of crisis. The first of these are the hardships which are a result of the initial source of stress; these hardships force the parents to take additional responsibilities as the condition of the disability hinders independent functioning in the child and if this added responsibility is not promptly resolved it can contribute significantly to family distress. The second stressor according to McCubin and Patterson (1983), are the normal transitions that take place within the family, for example, in addition to the initial event, the child’s school transition can pose additional demands on the parent as this change would require the family unit to undergo readjustment to the already existing schedule. Thirdly, any residual stress can be exacerbated by new stress imposed on the family requiring readjustment. Yet another variable that impacts the pile up of stress are the efforts of the family to cope with the situation, ineffective coping can result in increased levels of strain placed on the family. Lastly, ambiguity or uncertainty of roles can also lead to more strain in an already existing crisis.

Bb: (Existing and new resources) The Double ABCX model refers to the family’s adaptive resources as the “bB” factor. During a crisis a family uses two types of resources which are: existing and expanded family resources. Existing resources as the name suggests are already embedded within the family and work to minimize the impact of the stressor. Expanded family resources are the novel resources families generate to decrease the strain they are under, these resources can come via individuals, family or community. Both existing and expanded family resources help to create equilibrium and aim at providing stability to the family undergoing the crisis. An important resource in this factor is social support and the authors note that families who develop social resources are better apt to adaptation and recovery from a crisis as opposed to the ones that do not (McCubbin & Patterson, 1983).

Cc: (Perception of x+aA+bB) The "cC" factor within the Double ABCX model represents the meaning the family endows to the entire crisis situation. The family has the ability to redefine and give new meaning to the entire crisis making it more manageable to clarify issues and solve problems therefore facilitating healthy family coping. Within the family, this lessens the emotional intensity of the situation and enhances the social and emotional development of the family members.

Coping (BC): McCubbin and Patterson (1983), suggest that coping (BC) is a bridging concept that brings together cognitive and behavioural components so that resources (bB), perceptions (cC) and behavioural responses interact in order to restore balance in the family.

Xx: The last factor within this model "xX" refers to the ability of the family to balance between relationships amongst individual members, the entire family unit and the community that resulted from a crisis situation. According to this model, a demand capability imbalance creates stress when the demands placed are exceeding the capabilities of a family. In reference to the present study, this imbalance will when the care demands of the child exceed the family resources to care for the child thus requiring the family to negotiate ways to create a balance between their child and other members within the family.

Within the Double ABCX model, adaptation plays a crucial role as it aims at achieving balance, restoring and improving family functioning that has been disrupted through a crisis. The authors of this model suggest a balance between community and family is highly crucial as the community can impose difficult demands on the family resulting in a demand-capability imbalance. With relevance to this thesis this imbalance can be particularly difficult to deal with for parents of children with developmental disabilities. For example, a parent needs to find ways to meet the care needs of the child ensuring at the same time that their responsibilities at their work place are being met, and therefore community responsibilities have to be balanced with personal duties to attain equilibrium. It is important for families to gain a balance to achieve a sense of family coherence. Coherence is the ability within the family to experience an enduring feeling of confidence that the environment is predictable and situations will be navigated successfully and is vital for the family for successful adaptation (Peer, 2011).

According to McCubbin and Patterson (1983), family outcome falls on a continuum between negative maladaptation and bonadaptation. Maladaptation is the negative end of the continuum and is defined as a continued imbalance between the pile-up of demands and the family's capabilities for meeting those demands, example characteristics may include, deterioration family members' sense of well-being, physical and mental wellbeing or their psychological health (Lavee, McCubbin & Patterson, 1985). Bonadaptation, on the other hand lies on the positive end of the continuum, is characterised by a minimal discrepancy between the pileup of demands and the family's capabilities, so as to achieve a balance in family functioning (Lavee, McCubbin & Patterson, 1985). According to McCubbin and Pattrerson (1983), family coping can lead to eliminate or avoid the stressor; to manage the stressful situation; to maintain the family integrity; to develop resources to manage the situation and to make changes to adjust to the demands placed by the stressful situation. Coping thus plays an important role in deciding whether or not adaptation is achieved within a family.

As in Lazarus and Folkman’s (1984) Transactional model, where stress is managed through emotion focused or problem focused coping, in the Double ABCX model coping comprises of both cognitive and behavioural components. Within this model, families can either make changes to adapt and eliminate the stress or practice techniques such as avoidance to minimize the emotional impact of the situation or gather and develop resources to manage the situation effectively. Alongside the transactional model of stress and coping (Folkman & Lazarus, 1984), ABCX model (Hill, 1958), and the Double ABCX (McCubbin and Patterson (1983) collectively offer an insight into the aetiology of stress and coping for both individuals and families and provide a theoretical input for understanding the causes of stress for parents of children with developmental disabilities. These theories offer insight into how parents perceive stress and how this appraisal can then help to initiate, reappraise and maintain the coping response.

Summary and conclusions

This chapter describes in detail the concepts of stress and coping and the transactional theory of stress and coping, which focus on the role of the cognitive appraisal, defining stress not dependent so much on stable traits such as personality but rather as a dynamic process, incorporating the psychological processes of appraisal, coping and emotion (Folkman & Lazarus, 1985). Lazarus and Folkman (1984) suggested, that coping is most effective when there is a match between the characteristics of the stressor and the type of coping applied to the situation. It further details the Double ABCX model of family stress, which applies the transactional theory (Lazarus & Folkman, 1984) to families dealing with stress, this model can be used to understand the aetiology of stress and the impact of coping style and its relevance to the family unit. As in the transactional theory, the ABCX and Double ABCX model of stress highlight the importance of appraisal and evaluation of resources within a family to determine whether a situation is manageable or not. These theories also provide a framework for the various coping strategies that these families may use to deal with potential stressors. As this thesis aims to develop an intervention, the theoretical models chosen provide the 'building blocks' for this coping intervention design, implementation and provide a means for testing their effectiveness (Rutter and Quine, 2002). The models chosen for this research study contend that the way in which an individual interprets a stressor determines how they respond to in terms of their appraisals, emotional reactions, behavioural responses, and coping efforts. This interpretation is influenced by factors such as personal and social resources as well as characteristics of the stressful experience. It is therefore important to acknowledge this ongoing process of coping and understand that it may intervene differently for different individuals in different stressful situations.

CHAPTER 4

Methodological and Ethical considerations

The aim of this chapter is to address the methodological and ethical principles underlying this thesis. It begins with introducing the research design, including the underpinning epistemological stance and ontological position before providing a rationale for each specific study and associated ethical considerations.

Shih, (1998) proposes that a researcher's experience, their view of the world, understanding of philosophy and personal beliefs alongside the goal of the research, nature of the research question and nature of the phenomenon of interest may all have a bearing on the method adopted for research. The methods adopted for this thesis stemmed from a pragmatic empiricist ontological position and focused upon the ultimate development and evaluation of a psychological intervention. The pragmatic research philosophy enabled the adoption of mixed methods for data collection and provided the researcher with an opportunity to be both objective and subjective in analysing the data gathered (Saunders et al., 2009). The self-help coping intervention, which can be classified as a complex intervention based on its components, function and outcomes, was designed following the steps outlined in the MRC framework (2000; 2008) for developing complex interventions.

While considering the broad methodological framework for this research, the researcher's own philosophy was examined in relation to the aims of this project, methodology, and data collection. The first section of this chapter discusses the research paradigm in relevance to this thesis, followed by a discussion of the research methods and associated ethical considerations used in this study.

Research Paradigm

A research paradigm can be defined as a set of beliefs and feelings of the researcher about the world and ways in which this can be explored and studied (Denzin & Lincoln, 2003). The research paradigm reflects the worldview of the researcher and aspects of the mind, reality, reason, truth and proofs of knowledge (Hughes, 1994). A research paradigm, according to Guba and Lincoln (1994), can be characterised through its ontology, epistemology and methodology. A researcher’s ontological and epistemological perspectives create an integrated view of how the researcher views knowledge and how they then view themselves in relation to this knowledge, and the methodological strategies they use to un/discover it. A number of theoretical paradigms are discussed in literature such as: positivist (and postpositivist), constructivist, interpretivist, critical, pragmatic and deconstructivist etc. A brief explanation of the three most common paradigms and justification of its selection or rejection for this study are provided in the following section:

Post-positivist and Positivist paradigm:

Positivism is also referred to as the 'scientific method' or 'science research'; according to its proponents, positivism is based on a rationalistic, empiricist philosophy and “reflects a deterministic philosophy in which causes determine effects or outcomes" (Creswell, 2003, p.7). The aim of positivists is to examine a theory or describe an experience by the means of measurement and observation by using conventional scientific methodologies (Bassey, 1995; O'Leary, 2004). Researchers with a positivist orientation make efforts to verify a priori hypothesis that is quantifiable and can be verified through means of calculations expressing functional relationships (Guba & Lincoln, 1994; McGrath & Johnson, 2003). They aim to provide an explanation that leads to the prediction and control of phenomena. As the positivists believe in an objective reality, which is measurable and known, they advocate the use of quantitative methods to measure this reality. Positivism thus, relies heavily on experimental methods and lays importance on objective research methods that focus on quantitative analysis, surveys, experiments and the like.

The post-positivist philosophy argues that reality is a creation of the individuals involved in the research; therefore, it can be considerably influenced by its context making different constructions of reality a possibility (Hughes, 1994). This reality construction may also be influenced by factors such as personal, gender and cultural beliefs. Unlike the positivists, the post positivists hold that human intellectual mechanisms are variable and flawed and therefore, one can never fully capture a “true” reality. Post-positivist approaches propose that reality is multiple, subjective and mentally created by the researcher’s interaction with the researchee and the research findings are thus an outcome of an interactive process which aims to provide a meaning and understanding of the phenomenon being studied. This approach gives way to critical multiplism where both objective and subjective realities can be studied for research inquiry (Guba & Lincoln, 1998). Despite underlying differences between the positivist and post positivist paradigms, the two perspectives share some common ground (Lincoln & Guba, 2000; Ponterotto, 2002), wherein both these paradigms aim to provide an explanation which leads to prediction and control of phenomena and emphasize cause–effect linkages which can be studied, identified, and generalized.

Interpretivist / constructivist paradigm:

Interpretive research is more subjective than objective. Willis (2007) argues that the goal of interpretivism is to value subjectivity, and “interpretivists eschew the idea that objective research on human behaviour is possible” (p.110). According to this paradigm the nature of inquiry is interpretive and its purpose is to understand a particular phenomenon, and not to generalize it (Farzanfar, 2005). This approach to research aims to understand the world of human experience (Cohen & Manion, 1994), the “lived experiences” from the point of view of those who experience (Schwandt, 2000) because according to this philosophy reality is socially constructed. The interpretivist/constructivist paradigm recognises the impact of their own background and experiences on the research and base their findings upon the participants' views of the situation being studied (Creswell, 2003). Constructivists argue that reality is the by-product of the mind of the individual, rather than it being an externally singular entity (Hansen, 2004). Unlike the positivists and post positivists, the constructivists do not start with a theory but rather generate it inductively through a pattern of meanings throughout the research process (Creswell, 2003). These theorists believe that reality needs to be interpreted and follow a hermeneutical approach, which suggests that meaning is hidden and must be brought to the surface through deep reflection (Schwandt, 2000; Sciarra, 1999), which can be stimulated by an interactive researcher–participant dialogue. A distinguishing characteristic of constructivism is the importance of the interaction between the investigator and the object of investigation to uncover deeper meanings (Ponterotto, 2005). The researcher and the participant create (co-construct) findings together from their interactive dialogue and interpretation. Advocates of constructivism–

interpretivism emphasize that it is important to understand the “lived experiences” from the point of view of those who experience (Schwandt, 2000). Therefore, this paradigm lends the primary foundation and anchor for qualitative research methods. Additionally, a combination of both qualitative and quantitative methods (mixed methods) is also acceptable when quantitative data is utilised in a manner in which it may support or expand upon qualitative data and effectively add to the description of the phenomenon under study.

Pragmatic paradigm

Pragmatists do not commit their philosophical stance to any one system of philosophy or reality. The focus of research for the pragmatic researcher is on the 'what' and 'how' of the research problem (Creswell, 2003, p.11); they prefer a more balanced and reasonable version of philosophical stances based on how these contribute towards resolving a problem. According to the pragmatists, the research question is the ultimate determinant of the research philosophy, they recognize the research problem as central; and relevant tools for data collection and analysis are identified with the aim of providing insights into this central question with no philosophical loyalty to any alternative paradigm. In pursuit of advancing knowledge, pragmatists advocate that taking a balanced or pluralist position where research methods are mixed to enable ways of identifying methods to answer important research questions is ideal (Hoshmand, 2003; Maxcy, 2003).

Advocates of this approach argue that because the nature of reality is such that it is continually renegotiated, debated, and interpreted, the ideal way to understand it is to use a method which may solve this problem. Thus, based on the nature of enquiry, pragmatists may incorporate both the positivist and interpretivist positions within the scope of a single research question which in turn gives way to a useful middle position philosophically and methodologically. The pragmatic paradigm is a practical and outcome-oriented method of inquiry which provides researchers with a selection of methodological amalgamations which can assist them to answer their research questions by intervening into the world of the participants and not merely observing it (Goldkuhl, 2012). However, Maxwell and Mittapalli (2010), argue that the pragmatists underestimate the actual influence of philosophical assumptions. They propose that these assumptions inevitably influence the researchers' purposes and actions to a certain degree and are often implicit and therefore cannot be easily abandoned or changed. They further their argument by giving an example, suggesting that mainstream quantitative research traditionally has a view of causation, an emphasis on replicability and general laws, and a validity strategy based on experimental or statistical controls. These characteristics of quantitative research and the philosophical position that informs these researchers, inherently relegates qualitative research to a secondary role in investigating causality. Researchers argue against Maxwell and Mittapalli (2010) and conclude that the consideration of pragmatism is rather advantageous as it provides an immediate and useful middle position philosophically and methodologically. Pragmatism is an outcome-focused method of inquiry which offers a selection of methodological mixes that may assist the researcher to get better answers to their research questions (e.g. Mackenzie, & Knipe, 2006; Morgan, 2007; Morgan,2014; Yvonne Feilzer, 2010).

The epistemological orientations to research according to Braa & Vidgen (1999) consist of, research which aims at explanation and prediction (positivist paradigm); research which aims at interpretation and understanding (interpretivist paradigm); and research which aims at intervention and change (pragmatist paradigm). Despite differences between research paradigms, there are possibilities for blending and combining paradigms for better research within the discipline of Psychology. Having more than one paradigm can offer the opportunity for a researcher to create a study where elements from various paradigms can be used in a constructive and supportive manner (Goldkuhl,2012).

Mixed methods and the pragmatic paradigm

Pragmatism has been put forward as the best paradigm for mixed methods research (Tashakkori & Teddlie, 2003) as it allows the researcher to use varied philosophical foundations for its justification and use through various ideas and diverse approaches depending upon what might work and integrating both objective and subjective knowledge (Cherryholmes, 1992). As Hanson et al., (2005), Tashakkori and Teddlie (2003), also advocate that more emphasis should be laid on the research question in comparison to the method or the paradigm which underlies this method. The present research has encompassed a pragmatic paradigm and the researcher has combined a interpretivist-constructionist position (the qualitative study of the thesis) where the world is socially constructed through various discourses and meaning systems (Burr, 2003; Faris & van Ooijen, 2012) and where it is impossible not to be influenced by one's particular beliefs and prejudices (Faris and van Ooijen, 2012) with a positivist approach where research aims to provide an explanation which may lead to prediction and control of phenomena (quantitative study of the thesis assessing the effectiveness of the coping intervention). In the discipline of Psychology, the interpretivist-constructionist paradigm emphasises on better understanding through first-hand experience, and true reporting of quotations in data to gain an insider's perspective to the research question rather than questioning the laws of human behaviour (Farzanfar, 2005). The interpretivist-constructionist collect data by using methods which are sensitive to context (Neuman, 2003), which may assist the participant to understand the investigator's quest for insight into a phenomenon they have experienced. This may then generate a rich and detailed description of the phenomena under study. As a consequence qualitative data collection for these studies may be done through either one to one interviews, focus groups or naturalistic observations. Sandberg (2005), advocates, that the ontological and epistemological assumptions of interpretive research dismiss the entity of an objective knowable reality, alternatively, they specify that knowledge is created through a lived experience of reality. Therefore, according to Sandberg (2005), interpretivist research cannot be based on an objectivist ontology and epistemology. The aim of the qualitative study in this research was phenomenological. It sought to understand participants' subjective experiences, seeking to discover what their experience of caring for a child with a disability is, what meaning do they make of this experience and how this lived world presents itself (Finlay, 2008, Howitt, 2013) giving the researcher an opportunity for insight into the lifeworld of participants (Creswell, 2007; Howitt, 2013).

The positivist paradigm, on the other hand emphasizes an objective approach to exploring social phenomena and lays emphasis on research methods based on quantitative analysis, surveys, or experiments. As discussed previously, the philosophical basis of the positivist orientation is that quantitative methodology can be used to discover a knowable world (Cohen, Manion & Morrison, 2000). The aim of the quantitative study of this thesis was objective as it sought to establish the effectiveness of the designed coping intervention on the stress levels and coping orientations and test the hypotheses framed in relevance to this question. With the aim to get answer to these research questions a pragmatic paradigm incorporating a mixed methodology was used for this research. The following section highlights the concept of triangulation and the justification of using mixed methods for this research.

Research Design: Intervention development and evaluation

The review of literature (Chapter Two) concluded that implementing any form of structured interventions has a positive impact over no support or the receipt of standard services to parents caring for children with developmental disabilities. A review of current interventions in this chapter (Two) also revealed that most of these interventions do not explicitly aim at helping parents to enhance their personal coping skills which may help them to prepare for and develop resilience against present and future stress. The present research study identified this gap and aimed therefore to develop a novel intervention which would aim directly at the parents' well-being. The self-help coping intervention leaflet developed for this study has been adapted from a previously used version which was aimed, created for and tested on a population of patients undergoing cancer genetic risk assessment (Bennet, Phelps, Brain, Hood & Gray, 2007; Phelps, Bennett, Hood, Brain & Murray, 2012). The adaptation and evaluation of this intervention was informed by the Medical Research Council's framework (2000) for developing complex interventions.

Often, complex interventions are not systematically developed, specified, or reported (Michie, Fixsen, Grimshaw, & Eccles, 2009) necessitating the need for an adherence to following a rather systematic process which may inform the development, evaluation and implementation, and aid in understanding the underlying processes of why and how an intervention works (Lakshaman et al., 2014). The MRC Framework for the development of complex interventions (2000; 2008), has been used widely to develop and evaluate interventions due to its flexibility and non-linear approach (Bobrow et al., 2018) with greater attention to early phase piloting and development work (Craig et al.,2000). The revised 2008 MRC framework lays greater emphasis on the piloting and feasibility stage, which in turn may significantly improve the intervention content and materials, evaluation tools, and recruitment strategies, this framework, was therefore considered most appropriate to the development and evaluation of the self-help coping intervention. Figure 4.1 shows the key elements of the development, evaluation, and implementation process of complex interventions as guided by the MRC (2000, 2008), these elements have guided the intervention development and evaluation in this thesis.

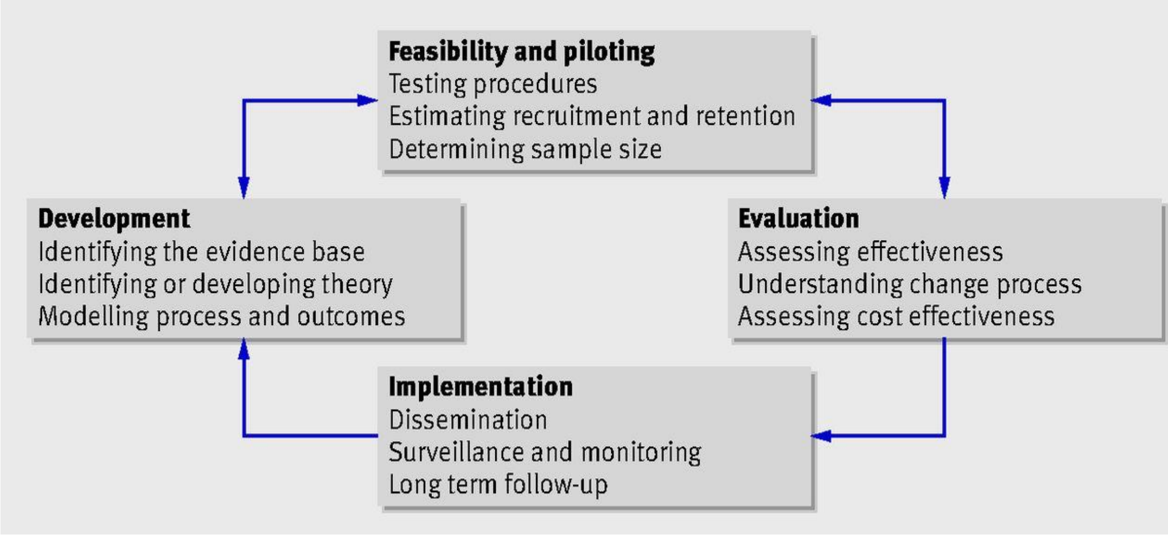

Figure 4.1 Key elements of the development, evaluation, and implementation process of complex interventions.

The process of the development and evaluation of complex interventions has several distinct phases; this phased approach was followed to guide this thesis as it sets out the objectives to be met at each stage prior to moving forward to the next stage. The phases in this framework are (1) 'Pre-Clinical' or theoretical (2) Phase I or modelling (3) Phase II or exploratory trial (4) Phase III or main trial (5) Phase IV or long term surveillance. Figure 4.2 shows the sequential phases of developing complex interventions.

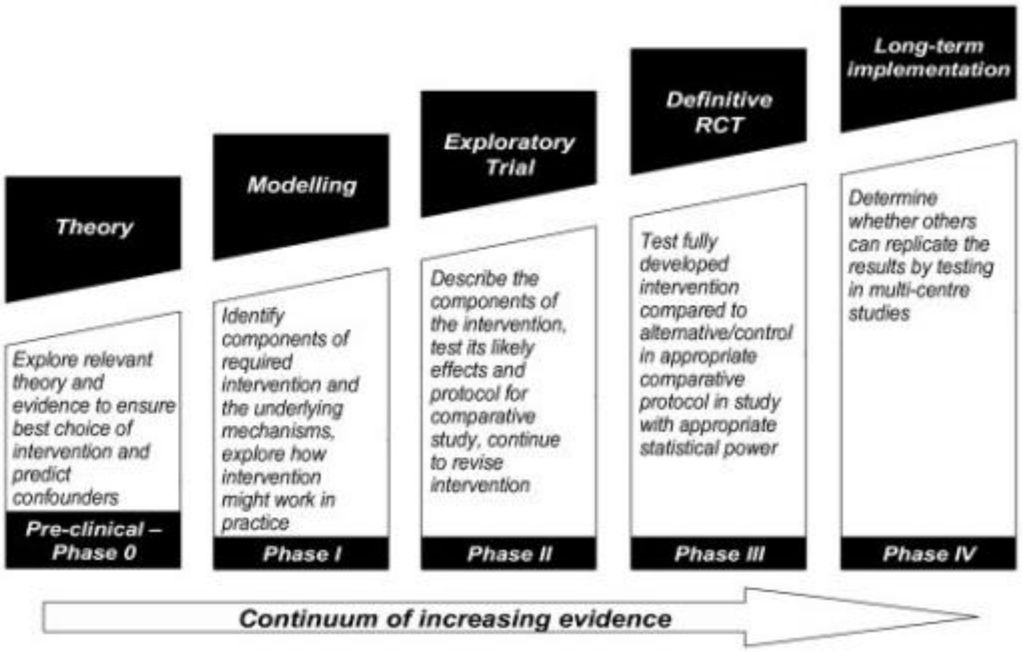

Figure 4.2 Sequential phases of developing complex interventions.

Phases from pre-clinical to Phase II were followed for this thesis. The first stage of developing a complex intervention according to the MRC (2000) framework is to identify the existing evidence (the preclinical phase). For the present study the literature review conducted warranted that the intervention can be reasonably expected to have a worthwhile effect on the target population. This stage also warrants a review to identify what is already known about similar interventions and the methods that have been used to evaluate them. The review of literature (Chapter Two and Three) identified similar interventions, their modes of delivery, evaluation and outcomes. The assumptions about the need and importance of a coping intervention were tested by an in-depth IPA qualitative study which highlighted the need for an intervention which may minimise stress in parents caring for children with developmental disabilities. Using evidence from the literature alongside the findings from the semi-structured interviews of parents it was agreed that a coping intervention would be helpful for parents to minimise their levels of stress. This stage (pre-clinical) was followed by the identification of relevant theories (Phase I) I.e. the transactional model of stress and coping (Lazarus & Folkman, 1984), and the Double ABCX model of family stress (McCubbin & Patterson, 1983), so the theoretical understanding of these may predict changes that are expected with the use of the intervention. The next step (Phase II) in developing a complex intervention is that of modelling processes and outcomes (MRC, 2000), this evaluation can help to refine the design and overcome weaknesses of the intervention before a full-scale evaluation is warranted. The second study of the thesis (Chapter Six) hence aimed to assess the self-help coping intervention in terms of its acceptability and feasibility amongst parents of children with developmental disabilities. Relevant changes were made to the leaflet based on the outcome of this exploratory trial. Lastly, the revised self-help coping leaflet intervention was assessed for effectiveness through a longitudinal quantitative study (Chapter Seven). The present research study used an iterative phased approach to harnesses qualitative and quantitative methods which leads to improved study design, execution, and generalisability of results (Campbell, Fitzpatrick, Haines, Kinmonth, Sandercock, Spiegelhalter, & Tyrer, 2000). For the objective of meeting the research aims of this thesis, a mixed-methods design was adopted, this method allowed the researcher to ensure that the deviation or similarity in the research findings were accounted for by the trait under study (stress and coping) and not merely by the method that was used to measure it (Teddlie and Tashakkori, 2003).

Triangulation: A between-methods triangulation approach was used in this research study as this strategy allows to balance the flaws of one method with the strengths of another; and as a result, researchers can achieve the best of each method whilst overcoming their unique weaknesses. For this study, qualitative data was gathered in the context of understanding a parents' experience of raising a child with a developmental disability and quantitative data was gathered to understand the prevalence of stress, coping mechanisms and the effect of using a brief self-help coping intervention. For the first qualitative study of this thesis the broad research question was related to the experience of caring for a child with a developmental disability, this question was the scaffold of the exploration and there were no predetermined hypotheses to test. The analysis process for this part of the research was therefore inductive which was driven by the data, rather than by existing theory and literature. However, because the quantitative data needed to be placed in the context of the findings of the qualitative study so relevant conclusions could be drawn, a triangulation of methods was used for this study. Fielding (2010) explains that triangulation in mixed methods research can be established through the combination of or conversion of quantitative and qualitative data. He proposes that it is reasonable to integrate the two for establishing a clear understanding of the phenomenon being studied. Triangulation is broadly defined by Denzin (1978. Pp 291) as "the combination of methodologies in the study of the same phenomenon." Campbell and Fiske1 (1959) developed the idea of multiple operationism in social sciences and suggested that in order to validate processes more than one method should be used so that the variance reflected is that of the trait and not of the method, thereby complementing the conviction that the results are valid and not a methodological artefact. This form of triangulation has been labelled as “between (or across) methods" type, and represents the most popular use of triangulation. It allows to cross validate when two or more unique methods are found to be confirming and produce comparable data. For example, the experience of stress and coping may be studied by interviewing the parent, observing his or her behaviour, and evaluating stress scores and coping techniques. The focus on stress and coping always remains the same but the mode of data collection varies. A variety of data and methods can be successfully blended and integrated in triangulation, providing a holistic, and contextual portrayal of the phenomenon under study (Jick, 1979). Quantitative and qualitative approaches can be successfully combined as both share the goal of understanding the world in which we live (Haase and Myers, 1988). Both approaches have a focus on disseminating knowledge for practical use, and a shared commitment for rigor, conscientiousness, and critique in the research process. Even though some researchers claim that both these methods are incommensurate as they stem from very different ontological and epistemological positions (e.g. Guba, 1987), Sale et al., (2002) argue that despite the approaches being incommensurate multiple methods can be successfully supplemented in a single study for complementary purposes.

According to Fielding (2010), the most frequently used mixed methods design is the combination of survey and interview data. About 57% of social science studies employ multiple methods by concurrently using a survey instrument with qualitative interviews (Bryman, 2006). The results of these studies may be co-analysed or analysed independently, for the findings to be compared. Essentially, the expectation from this design is not just mixing methods but evidencing that methods were mixed to be a feature of the analysis which could inform the final outcome of the study. Various authors suggest that when quantitative and qualitative methods are used together, they complement each other and produce a more robust analysis (e.g. Bryman, 2006; Ivankova, Creswell, & Stick, 2006; Tashakkori & Teddlie, 2008). In the present study, qualitative and quantitative methods do not merely use the strengths of each method to bolster the weaknesses of the other; rather, they provide an additive outcome as mutual research partners. The aim of the qualitative study (study one) in this thesis is phenomenological as it aims to understand the participants' subjective experiences, which in this case is the experience of caring for a child with a developmental disability, the meaning the parents /participants make of this experience and how this lived world presents itself (Howitt, 2013). To be able to meet the aims of the qualitative study, wherever possible, elements from phenomenology were used, considering it as complementary to the values and philosophy of the researcher. For the quantitative study of the thesis, there was a focus on deduction, confirmation, hypothesis testing, explanation, prediction, standardized data collection, and statistical analysis.

Both methods have been combined to use the results yielded from one method (Study One) to add and elaborate on results from the other method (complementarity) (Study Three); use results from one method (Study One) to help develop or inform the other method (Study Two) (Goodyear et al., 2005, and Beck, 2005), recast results from one method to questions or results (Study Three) from the other method (Study One) (initiation). To elaborate, an exploration of the stress experienced by parents caring for a child with a developmental disability along with their preferential ways of coping are explored in depth (Study One) with the aim to inform and facilitate the quantitative study (Study Three) which measures their levels of stress and ways of coping through survey instruments. The integration

(Study One and Study Three) will be done during the interpretation of the results of both the studies in order to draw appropriate inferences and conclusions of this research. Findings from Study One will also be used as a guide to develop and inform Study Two. Although the phenomenon of under study (stress and coping) will be common across methods, the distinction between “lived experience” and “measure” will differentiate and yet integrate this phenomenon to its respective method (qualitative and quantitative) and paradigm (interpretivist and positivist).

Qualitative Research (Study One and Study Two) : Qualitative research and data collection was considered ideal in order to answer the first research question set out in this thesis which seeks to explore participants’ perceptions and experiences and understand processes rather than determine outcomes (Smith, 1996). Varela and Shear (2001), assert that the first-person perspective in qualitative research provides an experiential account of the event under scrutiny; where the first-person event refers to a lived experience. Qualitative research methods in the discipline share certain common principles such as the aim to understand how people perceive the world and how they experience life events (Willig, 2003). This approach also connected with the foundation of the aim of this study is about a search for experiential meaning, rather than number-based outcomes, and sought not to provide a single correct answer, but rather to explore the plethora of feelings of parents about their caring role. Consequently, it was acknowledged that meaningful answers to the research question could be offered (Lincoln and Guba, 1985) through a qualitative [inductive] approach rather than a quantitative, deductive approach (Creswell, 2013). A qualitative approach was also desirable for this study as there was a requirement for openness towards the participants’ experiences, so that their voices could be heard and interpreted whilst keeping in mind the influence of the interactions between the researcher and participants (Ponterotto, 2005; Rennie, 2012; Creswell, 2013). Accordingly this knowledge, constructed by both researcher and participants (Lyons, 1999), would create an understanding of how participants describe their perceptions of caring for a child with a developmental disability. Based on their epistemological assumptions and method of data collection and analysis, different qualitative approaches define different dimensions of psychological phenomena and ways of interpreting data. Although there is considerable variety in these qualitative methodologies, they can be broadly summarised within four principal approaches (Charmaz, 2003,2006, 2008; Lyons & Coyle, 2007; Smith, 2003; Willig, 2003): grounded theory, the phenomenological approaches, discourse analysis and the narrative approaches.

Grounded theory: Sociologists Glaser and Strauss first put grounded theory forward in 1967 with the aim of studying social processes from an inductive approach. They argued that in order to understand social phenomenon it is imperative to be able to generate theory at various levels (Glaser and Strauss 1967; Glaser 1978). Therefore, proponents of the grounded theory endorse that an approach which is concerned with the meanings, definitions, and interpretations which are made by the participants have a great potential for depicting their world and priorities in comparison to methods which commence with a preconceived idea of the world and its meaning (De Burca and McLoughlin, 1996). The aim of Grounded Theory is developing a theory that is precisely secured with evidence, and is compatible with empirical data (Orlikowski 1993; Eisenhardt 1989). This method is better suited to understand the unfolding of social processes. However, Willig (2003) cautions that grounded theory approaches are oriented towards developing a map of categories with the aim to describe and conceptualise the processes of the problem at hand, and hence, are not able to provide answers to questions about the nature of experience. For the present research, Grounded Theory was not considered as an alternative as it did not align with the objective of this research which was mainly explorative and did not intend to generate theory (Creswell, 2007).

Discourse Analysis: Discourse Analysis (Burman and Parker, 1993; Wetherell et al., 2001a, 2001b) evolved from linguistic studies, literary criticism, and semiotics (Starks & Trinidad, 2007). It recognises that speech cannot be regarded as a direct representation of human experience, but rather as an explicit linguistic tool which is constructed and shaped by a number of social or ideological influences. Theories in disciplines such as sociolinguistics and cognitive psychology inform discourse analysis as they aim to understand and explain what is represented by language or the various ways in which people communicate ideas (Thorne, 2000). Discourse Analysis offers the researcher a way by which they can contemplate and comprehend a participants' description of themselves, a particular phenomenon and their social worlds (Shotter, 1993). Discourse analysis was not considered a suitable approach for the present study as the goal of this method is to understand how people use language to create and enact identities. The present research question however aimed at exploring the experience of stress and coping amongst parents and hence had a different goal which aimed to address how meanings are produced and re-interpreted from the perspective of the individual.

Narrative Analysis: Proponents of Narrative Analysis claim that communicating through telling stories is a natural human impulse (White 1981). They propose that people are able to express their identity, relationships and emotions through these stories (Priest, Robert & Woods, 2002). According to Bruner (1991), all experience is filled with 'meaning', and stories, rather than logical arguments or lawful formulations, and these stories are how that meaning is communicated in everyday life. The goal of Narrative Analysis is to treat data as stories, to consider and focus on this storied nature of human behaviour, as these stories come with a potential to provide meaning to people's lives, (Emden 1998). As a psychological research method aiming to gain an insight into the lived experience, narrative approaches focus on how individuals organize significant life events by applying the meanings available at times of personal uncertainty (Denzin, 1990), however, the many ways in which these personal narratives or stories are reconfigured in light of one’s own experience is not considered. This drawback thus evidently gives rise to the question of how these narratives or stories operate as an instrument in the construction of reality and what is their potential in organizing the structure of human experience which is filled with inherent meaning rather than logical arguments or lawful formulations (Bruner, 1991). As the research question of this study aimed at understanding the meaning of a lived experience of a parent it was decided that a narrative analysis would not be the ideal approach to justify the aim this study.

Phenomenological approaches: A phenomenological approach was chosen for the qualitative study (Study One) of this thesis as it can be justified by the philosophies of the researcher and the research question. As contemplated, this research is about the experience of parenting a child with a developmental disability and thus aligned well with phenomenology and exploring the lifeworld (van Manen, 1990) of the participants. As Creswell (2013) elaborates, the best problems for exploration via phenomenology are those where it is important to understand the experience of an individual. Phenomenology aims to study the conscious experience as experienced from the subjective or first person point of view and was initiated by

Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty, Jean-Paul Sartre, et al. in the first half of the 20th century. Phenomenological psychological approaches aim to elucidate the participants lived world and seek to remain as faithful as possible to the rich contextual examples of the lived experience (Giorgi, 2003). Thus, the use of a phenomenological approach can be justified in the present study which aims at understanding the participants lived experience of caring for a child with a developmental disability. The focus of the phenomenological approaches is on the study and systematic examination of experience (Finlay, 2008); the two principal approaches to phenomenological research are categorized as descriptive and interpretive. The descriptive phenomenological approach requires more attention on the structure of the phenomenon itself and how the detailed description of the participants will allow the unravelling of its psychological essence. This approach suggests that the 'pure' description of the participants' narratives is a transparent manifestation of what is happening to them and the interpretative dimension of analysing the accounts is not incorporated in the methodology (Reiners, 2002). This approach is less concerned with examining how the participants make sense and interpret their lived experience, which is a key component of the interpretative phenomenological approach (Smith, 2007) which aims to gain a greater insight into the nature of phenomena as it unfolds.

The Interpretative Phenomenological Approach (IPA) was considered ideal to meet the aim of exploring experiences through engaging with a theory of interpretation whilst attending to the individual and the particular. The IPA is strongly influenced by hermeneutics and this element facilitated the social interaction between the researcher and the participant, encouraging the researcher to bring her perspectives and interpretations to the analysis (Shinebourne, 2011; Smith

1996) in a way that meanings of experiences could be jointly constructed, leading to a double hermeneutic (Smith and Osborn, 2003; Wagstaff, & Williams, 2014) where two interpretative stances work collectively (Shinebourne, 2011; Smith, 2011, Ricoeur, 1970). The first is, the hermeneutics of empathy, which focuses on understanding the meaning of each text as seen (Langdridge, 2007) and the second, the hermeneutics of suspicion, or, as Smith, Flowers and Larkin (2009), aptly define, the hermeneutics of questioning, engaged with existing theoretical perspectives to unpack hidden meanings of experiences. The participant tries to make sense of their personal and social world; the researcher tries to make sense of the participant trying to make sense of their personal and social world and underlying this process is a spirit of openness (Smith, Flowers and Larkin, 2009) where the interpretative account is iterative, formed from the relational encounter between researcher and the participant. In summary, as Smith et al., (2009) propose: IPA requires a combination of phenomenological and hermeneutic insights. It is phenomenological in attempting to get as close as possible to the personal experience of the participant, but recognizes that this inevitably becomes an interpretative endeavour for both participant and researcher. Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen (Smith et al., 2009, p.37). The hermeneutic approach of the IPA provides opportunities for interpretative analysis, contextualising participants' accounts in reflections and relevant theoretical material, thus making it possible to link the findings to psychological literature (Shinebourne, 2011).

Idiography is the third theoretical underpinning of IPA and is likened with the study of an 'individual' in psychology, it draws upon individuals as they deal with specific situations or events in their lives (eg, Robson, 2002; Smith, 1999). The idiographic commitment of IPA is aimed at the in-depth study of particular instances, either as single case studies or in studies of a small group of cases thereby offering an opportunity to the researcher to learn about an individual in a specific context, as well as simultaneously focusing on the unique aspects of a particular account. The result of an IPA analysis usually takes the form of a more idiographic interpretative commentary, interwoven with extracts from the participants' accounts (Smith, 2009).

To summarise, the IPA has an interpretive ontological stance and is committed to the examine how people make sense of major-life experiences (Smith et al., 2009). IPA focuses on the process of meaning making itself, which is the way an individual interprets their lived experiences. It pays much attention to how people make sense of their life, working directly with subjectivity as a dynamic interplay of various psychological events such as cognition, emotion and linguistic repertoires. As a phenomenological research method, it makes use of a detailed description, and is interested in gaining an understanding of the particularity of each individual's perception. The aim of this method is not to attempt and define facts or even to seek the truth. It rather aims to understand an individual's own experience, the meaning they make of it and, crucially, the interpretation that the researcher makes of this meaning.

In regard to the research questions proposed for this investigation, it has become clear that the focus of inquiry is directed towards the understanding of the experience of parents caring for a child with a developmental disability and how they cope with this situation. The IPA delivers a holistic template suitable for building an understanding of the process of caring for a child with a developmental disability as a lived experience. It enables a comprehensive and thorough examination of the psychological world of the parents as they raise their child. The IPA stands out as a true psychological research approach in that it can examine how discourses shape people’s interpretative repertoires in the use of language, and how their world is discursively constructed (Smith et al., 1999). This approach regards the participant’s narrative as a means to investigate their life-world, whilst acknowledging that this is also an interpretative process (Eatough & Smith, 2006). The process of interpretation as suggested by Smith (2009, 2011) is more than the application of previously integrated meanings; it is an active process of formulation, reconsideration and revision, possible through a self-interactive process both from the point of view of the participants and the researcher. This approach is hence pivotal to an insightful analysis that does justice to the complexity of human psychology.

IPA has much strength as an evolving research methodology, but is not without limitations. As it is a relatively new evolving methodology (Larkin et al., 2006) and some variations exist in the way it is applied and such anomalies can be confusing for novice researchers drawn to IPA for research projects. IPA in the past has been condemned for the long data collection process it entails, for example, the commitment and time involved in conducting semi-structured interviews and consequent in-depth analysis of data (Rabionet, 2011), however, this can be contended as this is a concern common to all qualitative research and is not specific to IPA’s methodology. Highlighting the drawbacks of IPA, Willig (2003), challenges the suitability of participants’ accounts arguing that participants may not be able to successfully communicate the rich texture of their experience to the researcher; this argument again is a common concern to most qualitative researchers and not just the IPA, however, the variedness of data collection methods such as in-depth interviews, diaries, focus groups and observational methods; all have been successful in accessing rich and nuanced data (Larkin & Griffiths, 2002).

The considerations discussed above offer an insight into how IPA is fit for purpose in the context of aiming to provide an answer to the first question of this thesis which aims to understand how parents perceive their role as a primary giver to a child with a developmental disability and their perception of stress and efficacy in coping associated with this role.

Thematic Content Analysis: The ‘thematic content analysis’ approach was used for identifying, analysing, and reporting patterns (themes) within data (Braun & Clarke, 2006) for this study (Study Two). The second research objective of this thesis was to develop and assess the acceptability of a self-help coping intervention developed to promote the effective use of coping strategies which aim to provide opportunities to reduce stress in parents of children with developmental disabilities. As for the IPA, some background to this method is provided to aid understanding of the analytical process, provide transparency, and strengthen trustworthiness.

Thematic Content Analysis, is essentially independent of theory and epistemology, making it a flexible and useful research tool, providing a complex yet rich and detailed, account of data (Braun & Clarke, 2006). It has been recognised as an ideal method for the identification, analysis and reporting of patterns or themes within data (Braun & Clarke, 2006). The variability and fluidity of thematic analysis make it appropriate for a variety of research projects and like the Interpretative Phenomenological Analysis (Smith, Flowers and Larkin, 2009) detailed in the previous section, thematic content analysis seeks patterns within data. Yet unlike IPA, thematic analysis immediately encompasses an entire data set and is not tied to any particular epistemological position (Braun and Clarke, 2012). According to Braun and Clarke (2006), thematic analysis is merely an analytical method, however, they emphasise that the researcher should acknowledge and make clear their underlying values, philosophical background and theoretical stance towards qualitative research. These considerations and the ontological and epistemological stance of the researcher and the research have been outlined earlier (page 107-108).

An inductive semantic approach was considered ideal for this study, that is, the themes identified were firmly linked to the data themselves (Patton, 1990). The inductive form of thematic analysis is data driven which suggests that if data collection was specifically for research purposes (e.g., either through interviews or focus groups), the themes identified may not be influenced by the researcher's theoretical interest in the area or topic. Inductive analysis aims to code data without any bias of the researcher's analytic preconceptions or without trying to fit this data into a pre-existing coding frame (Braun & Clarke, 2006). However, the authors reiterate that it is not reasonably possible for researchers to free themselves of their theoretical and epistemological commitments. Concerning the semantic approach, the themes are determined within the explicit or surface meanings of the data, and the analyst does not aim to explore for anything beyond what a participant has reported. The process of analysis in this case evolves from description, showing patterns in semantic content, and summarized, to interpretation, where an attempt is made to theorize the significance of these patterns and the broader meanings and implications these may hold (Patton, 1990).

Thematic content analysis was considered an appropriate method to address the interview data where analysis was both semantic, as coding was undertaken on the basis of participants' experiences, and inductive as there were no analytic preconceptions (Braun and Clarke, 2012). Braun and Clarke also stress that clarity regarding the process of thematic analysis is essential (Braun and Clarke 2006) and accordingly, the way analysis progressed is detailed within Chapter Six.

Quantitative Research (Study Three)

As discussed earlier in this chapter (page 105-108), this thesis follows a pragmatic approach in which it incorporates both qualitative and quantitative research methodologies. This triangulation was influenced by the topic to be researched; the objectives; and the specific proposed research questions for each of the studies forming this thesis. The third and final study of this thesis was designed to be a quantitative study which was an exploratory trial of the effectiveness of the self-help coping intervention. This quantitative study was informed by the MRC Phase II exploratory trial guidelines (MRC, 2000), which stipulate that the trial should be able to provide information about the effectiveness of the intervention and assess the leaflet (intervention) in terms of its acceptability, usage and theoretically expected treatment effect which is lower distress in this study. According to Creswell (2009), a quantitative research approach is an investigation into a social or human problem, based on testing a theory composed of variables, measured with numbers, and analysed with numerical procedures, in order to determine whether the prognostic generalizations of the hypothesis hold true (Creswell, 2009).

The final study of this thesis aimed to examine the levels of stress and ways of coping. Accordingly, the primary interest of this study was to examine the impact of the leaflet on the key outcome measures of levels of distress and ways of coping at baseline and after the use of the leaflet at two follow-up time points over the course of three weeks. The research questions for the intervention analyses were aimed to compare levels of psychological distress pre- and post-intervention; to compare the impact of the intervention on coping strategies and to identify possible sub-groups of participants who may be more (or less) likely to benefit from such as intervention. In order to answer these questions a quantitative online longitudinal exploratory intervention study was conducted to study a single sample (within subject) over a short period of time with the aim of identifying or understanding any change caused by the proposed intervention (Streisand, Rodrigue, Houck, Pole & Berlant, 2000; Duncan et al., 2007).

According to Lazarus (2000), stress and coping research should follow a within-subjects and prospective longitudinal design for the researcher to be able to identify changes or processes in psychological reactions over time and diverse conditions. He suggests that the questions addressed by between-persons research designs are very different from those addressed by within-persons designs therefore; correlations amongst coping may vary considerably depending upon whether it is studied in the same person across occasions or in different persons on the same occasion. He concludes by stating that stress and coping research may benefit if these events are studied more closely (microanalytically), in depth, longitudinally, and more holistically as people cope with stress (as process), think (appraise and construct relational meanings), want, feel, and act in their struggle to advance their interests and adapt. Therefore, the rationale to conduct a within subjects study design for the present study was based on the nature of the research question which aimed to establish a relationship between the use of the intervention and coping and it was considered appropriate to acquire repeated observations on the same participants so this relationship could be established firmly. Due to the nature of this study (within group study design), the results miss a direct, concurrent comparison group, however, the results obtained provide the desired information on the efficacy of the intervention (Paulus et al., 2013). The lack of a control group also limits the generalizability of the findings, however, there was no comparison hypothesis drawn between groups and hence it was not warranted to have a control group for this study. Pragmatic reasons such as difficulty in recruitment within a limited period of time were also considered to make the decision to conduct a within subjects design as it created an allowance for number of participants to remain in just one study group as opposed to dividing them into further (intervention and control) groups.

Conclusion

From the discussion above, and with reference to the aim of this research study and the research questions, a lack of evidence and very few studies on this particular area (self-help coping interventions) have justified the use of a pragmatic paradigm for this research. In addition, considering the philosophical worldview of how research should be conducted, it can be argued that to focus on just one view, approach and method may result in detracting the purpose of this research and hence, a combination of methods, views and approaches was considered as an alternative to address the aims and objectives of this research study. As discussed in detail earlier (page 106-108), the research question led to the choice of the research approach, as the use of either quantitative or qualitative approaches could not completely address the research problem, whilst a combination of these approaches resolved this dilemma (Creswell & Plano Clark, 2011). Thus, the researcher's choice of paradigm was dependent on the research question the study was aiming to find an answer to (Saunders et al., 2009). The inherent nature of inquiry of the problem in the present thesis is complex and in such a case a pragmatic approach can be utilised as this approach is considered appropriate to make inquiry into the complex phenomenon of social and natural contexts (Creswell, 2009). The pragmatic research philosophy enables the adoption of mixed methods for data collection which provides the researcher with an opportunity to be both objective and subjective in analysing the data gathered (Saunders et al., 2009). Hence, a research question addressed with a pragmatic approach allows the researcher to examine an area that may be of interest whilst entwining methods which are considered appropriate and may result in using findings in harmony with a recognised value system (Creswell, 2009). Pragmatism has been hailed for being an approach that has laid the scaffold for practical research by incorporating different perspectives resulting in more rich and varied research (Saunders et al., 2009). The pragmatic paradigm draws a balance between the deductive and inductive perspectives of thinking thereby offering practical answers for merging different paradigms. Consequently, it was contemplated that a pragmatic research approach would be practical and able to provide a better grounding to fully explore the complex phenomenon of stress and coping in parents of children with developmental disabilities as opposed to using a single method approach in this research.

Methodological & Ethical Considerations:

Quality in Qualitative Research: Morse et al. (2002) argue that without rigor, research is worthless, becomes fiction, and loses its utility. Therefore, reliability and validity in all research methods is of great importance. The positivist or realist paradigms evaluate the value of research in terms of validity and reliability; terms such as credibility, quality and trustworthiness have increasingly been adopted by qualitative researchers in order to assess value (Golafshani, 2003). In their seminal work in the 1980s, Guba and Lincoln substituted reliability and validity with the parallel concept of “trustworthiness,” containing four aspects: credibility, transferability, dependability, and confirmability. Over the past two decades, reliability and validity have been subtly replaced by criteria and standards for evaluation of the overall significance, relevance, impact, and utility of completed research (Guba, 1981; Guba & Lincoln, 1982; Lincoln & Guba, 1985;Morse et al., 2002). Howitt (2010) points out that a qualitative study that fulfils the criteria used to evaluate quantitative research such as reliability, validity and replicability, may exclude aspects of central importance to qualitative research. In the field of psychology criteria for judging validity of qualitative research are fundamentally less standardised and commit to more selectivity than those set out for quantitative research. It is therefore, important for qualitative studies to demonstrate cohesiveness by asking questions, using methods and making interpretations that are appropriate to the theoretical approach taken and to be clear about it's openness to evaluation (Yardley, 2011). Despite there being a substantial variability in how these concepts actually inform practice (Roulston, 2010), various flexible guidelines have been developed to provide a supporting scaffold to qualitative research (e.g. Tracy, 2010; Yardley, 2000; 2003;2011). These guidelines are intended to be applicable to all qualitative research, regardless of the specific methodology adopted. For the present study, the researcher aimed to follow Yardley's (2000) four principles to facilitate the assessment of quality and rigour in qualitative research. These are sensitivity to context, commitment and rigour; transparency and coherence; and impact and importance.

According to Yardley (2000) sensitivity to context may be established through demonstrating sensitivity to the existing literature and theory, the socio-cultural setting of the study and the information gathered from the participants. She suggests that the context of theory and an understanding created by previous investigators who have analysed similar topics is essential for any investigation. The researcher hence should be able to show sensitivity to the data – to illustrate, by not simply imposing pre-conceived categories on the data but rather by carefully considering the meanings generated by the participants. Yardley (2000) proposes that showing sensitivity to the context in which the study was conducted is paramount to facilitating credibility. She argues that it is important to have an awareness of the socio cultural setting of the study. This can be achieved at various levels, for example, it was ensured that the researcher was well aware of the wider context in which the research was situated. This involved familiarising with the extant literature on the parenting a child with a disability and the theoretical underpinnings of the methodologies used in this research study.

It was also ensured that the researcher was sensitive to participants' perspectives using open-ended questions (qualitative studies). The results section also endeavours to demonstrate the researcher's sensitivity to the data through conducting and describing an in-depth analysis and supporting arguments with verbatim extracts. Smith et al. (2009), argue that this gives the participants a voice in the project and allows the reader to check the interpretations being made. However, the socio-cultural setting of the study which includes the description of the sample characteristics (Yardley, 1999) was missing from the qualitative study as the demographic details such as age, marital status were not collected by the researcher for this phase of the study. On reflection however, it seems plausible that the results would have been more robust had these variables been included. The quantitative study of this thesis however, records these details of the participants.

Yardley (2008) further identifies four key factors for consideration in the commitment and rigour of a qualitative study thorough data collection, depth of analysis, methodological competence/skill, and in-depth engagement with the topic. Commitment and rigor in a qualitative study can be attained by the researcher by having an in-depth engagement with the topic, including thorough data collection, displaying expertise and skills in the methods employed, and by undertaking a detailed in-depth analysis (Yardley, 2017). To ensure methodological competence, the researcher attended a conference and speciality lectures on IPA, as well as consulting a range of relevant literature in order to develop related skills and knowledge. Whilst the rigour of this study will have been affected by the researcher's status as a novice qualitative researcher, and also practical constraints in terms of time and the available sample, the researcher has at all times aimed to carry out the study in a thorough and careful way drawing on available training and supervision. Tracy (2010) argues that rigour can also be demonstrated by selecting a sample that is appropriate to achieving the aims of the research. As discussed in this chapter previously, the homogeneity of the sample was in line with that expected in phenomenological research. Finally, Smith (2011) recommends that the analysis undertaken should be thorough and interpretative, identifying the prevalence of each theme and showing extracts from a range of participants. This instruction has been followed throughout the analysis and write up.

According to Yardley (2000; 2008), a coherent specimen of qualitative research must have a solid grounding in the methods used and their theoretical background. In order to establish the coherence of this study the researcher provided a detailed rationale for this study in the literature review and introduction; the theoretical background of thematic analysis and the IPA; and a reasoning of as to why these were considered appropriate over other qualitative methods in the previous sections. Yardley (2000; 2008; 2017) also suggests that there is a need for transparency to be maintained throughout the research process, she clarifies that the reader should be able to see clearly how the interpretation was derived from the data. The researcher has tried to be transparent about the procedures by including information about how the interview schedule was constructed, how the participants were selected, how the interviews were conducted and how the resulting data was analysed.

Finally, Yardley (2000) propones that a final feature of good qualitative research is that it has a sense of importance and impact. She specifies that the requirement for all research to generate knowledge that is useful – whether in terms of practical utility, generating hypotheses, or even changing how we think about the world. Yardley (2008) points out that there is no value in conducting research unless the findings have the potential to make a difference; the relevance of and need for this study has been outlined in the literature review and introduction. One of the aims of this thesis is to provide an in-depth analysis to the exploration of the established link between parental stress, coping and raising a child with a disability. The findings of the first two studies was aimed to guide the designing of an intervention (Chapter 4) which will aim to minimise daily stress in parents caring for children with developmental disabilities. It is hoped that this research will encourage parents and practitioners alike to reflect on possible implications for their own well-being and practice and inspire future researchers to continue with investigations in this area.

Identifying and considering ethical issues in research and intervention development are important for both moral (adhering to ethical principles or cultural conceptions of what is right and wrong) and practical (producing the desired impact) reasons (Carter et al., 2011). Key ethical concerns in studies of this nature may include issues related to infringing on people’s privacy, interfering with their right to freedom of choice and autonomy for the sake of promoting well-being (Guttman, 2017). The following section discusses some of the ethical issues pertaining to this study; the ethical considerations as outlined by the British Psychological Society code of Human research ethics (BPS, 2014) for all three studies in this thesis are discussed in the relevant chapters. The entire research study (Study One, Study Two and Study Three) was conducted with due regard to the Code of Human Research Ethics (BPS, 2014). Each of the studies also went through due university ethical scrutiny processes and were granted full ethical approval by the University of Wales Trinity Saint David Research Ethics Committee (study one, ref 1404132: April 2012; study two, ref 1404132: November 2015; study three, ref 1404132: May 2016).

The issue of generalizability: The word 'generalizability' is defined as the degree to which the findings can be generalized from the study sample to the entire population (Polit & Hungler, 1991). Instead of statistical generalisation, qualitative researchers generally aim for theoretical generalisation, providing insights that may be useful in similar contexts. Generalizability is based on the way things are and will lead to “expectability” rather than the predictability that characterizes quantitative research (Stake 1978, Schoefield 2002). Much of qualitative research is aimed to understand a specific issue or phenomenon in a certain population or ethnic group in a particular context, hence generalizability of qualitative research findings is usually not an expected attribute (Leung,2015). However, there is a rising trend of amalgamating qualitative research which makes evaluation of generalizability pertinent. It is hoped that the findings from this thesis can be generalised to the population of interest and motivate future researchers to continue with investigations in this area.

The Issue of bias/selective reporting: Bias is commonly explained as any influence that provides a distortion in the results of a study (Polit & Beck, 2014). According to Smith and Noble (2014) bias can occur at different stages of the research process, such as during the design if there is an incongruence between aims and methods that may increase the likelihood of bias; and also during the selection process as it relates to both the process of recruiting participants and study inclusion criteria. Successful research begins with recruiting participants who meet the study aims. In studies of a qualitative nature, bias can also occur at the data collection phase if a researcher's personal beliefs influence the way information or data is collected. During analysis, the researcher may naturally look for data that confirm their hypotheses or confirm personal experience, overlooking data inconsistent with personal beliefs. The researcher tried to avoid any bias in interpreting the findings and demonstrated rigour by adhering to the principles of truth value, consistency and neutrality (Denzin & Lincoln, 2011; Johnson & Rasuloava, 2016). In order to adhere to these, all data were interpreted cautiously with the aim of extracting maximum information regarding the stress these parents go through and, for the second study the strengths and limitations of the draft coping leaflet. For the quantitative study all data collected were used for analysis and reports thus generated. Steps were taken to reduce bias as much as possible however, the qualitative research paradigm delegates the researcher as an integral part of the process where the researcher can't separate themselves from the topic/people they are studying, and it is in this interaction between the researchers and researched that the knowledge is created (Mehra, 2002). The data transcribed from the interviews were analysed by the researcher and approved by her supervisor to ensure there was no bias in her interpretation of the results. Verbatim descriptions from the interviews were used to support findings and to maintain transparency and neutrality. The researcher tried to address the issue of bias in the results by trying to keep the two voices that of the researcher and the participant separate, she guarded herself against only seeing and reporting data which confirmed with her ideas or manipulating it to fit her expectations.

In terms of bias in the selection stage, there was a clear aim of exploring the well-being of parents caring for children with developmental disabilities and hence there was bias in recruiting parents who cared for these children, but this was an integral part of the study design. The sample size (study one and study two) were considered adequate for a qualitative study as homogeneity in qualitative studies can be achieved by sampling a group of people who share and can therefore offer insight into a particular experience (Smith et al, 2009). It was aimed that all data is analysed and interpreted in line with the existing body of knowledge in the area (evidenced in the discussion section of each of the study chapters).

The Hawthorne Effect: The Hawthorne effect concerns research participation, the consequent awareness of being studied, and possible impact on behaviour (Chiesa & Hobbs, 2006; 2008; Gale, 2004; Sommer, 1968). It can be defined as a change in a person’s normal behaviour, attributed to the knowledge that their behaviour is being watched or studied (Oswald, Sherratt & Smith,2014). Whilst the Hawthorne effect may inevitably occur to some extent in psychological research perhaps in the form of social desirability responding (Perinelli, & Gremigni, 2016; Van de Mortel, 2008), the nature of psychological research and the ethical frameworks which must be adhered to mean that failing to inform participants that they were part of a research study would be a significant breach of ethics and good practice (Brinkmann, & Kvale, 2008; Richards, & Schwartz, 2002). Therefore, efforts to minimise the impact of any such effects come from the rigorous choice and piloting of study materials. In the case of qualitative research these are addressed by ensuring for example, that questions are neutral or free from bias and would not lead to socially desirable responses (Agee, 2009; Mays, & Pope,1995). Another key issue facing research is that ethical considerations such as withholding information from the participant must be balanced against the pros and cons of what might be a perfectly controlled research study where the Hawthorne effect is accounted for. The BPS code of human research ethics (2018) also states that “This Code of Human Research Ethics expects all psychologists to seek to supply as full information as possible to those taking part in their research…” (BPS, Code of Human Research Ethics, 2018). The nature of this (interview) study was such that it was important for the interviewer and participant to build trust in order to ease the interview process and therefore it was not possible for this research to be conducted without the participants being aware that they were being observed.

It is also important to note that the focus of this and many other studies in Psychology is rarely on measuring absolute levels of the dependent variable but on establishing associations between the relationships between variables, for example, the association between stress and the diagnosis of the child or certain coping mechanisms the parents use. It is argued that if the study participants have been provided with the same level of information about the study and are subject to similar assessment procedures any impact of the research process will be controlled minimising the Hawthorne effect. For the present study all participants were treated equally in terms of the information provided and measures used to obtain results, the participants in the qualitative studies were also made to understand the importance of their views and the aims of this research. As suggested by Al-Yateem (2012), in order to obtain quality data from participants from a one-off interview it is important that there is a prolonged engagement with the participant, the interviewer should therefore allow time before interviews to tell participants something about themselves and create a feeling of being known. The researcher had made telephonic contact with all the participants prior to the study and had included all relevant information about the study on the information sheet. This gave the researcher a brief window in time to build a relationship of trust and respect with the participant not only to improve the quality of the data but also reducing the chances of findings to be influenced by the Hawthorne effect (Oswald, Sherratt & Smith,2014). At the start of each interview the researcher again introduced herself, explained about the study and its importance and purpose before engaging in a formal interview. The researcher had prepared herself well before the interview by having an interview schedule with prompts and alternative ways of asking for explanation with the aim to facilitate the flow of as much of a natural conversation as possible. Towards the end of the interview, the participants were asked if they wanted any further clarifications and were informed about the way they could get in touch with the researcher if they had any query. Even though it may be unlikely to completely forego an observer bias it was hoped that these steps would somewhat overcome the potential effects of being recorded on the participants.

Many of the interviews for the first two studies of this thesis were conducted over the phone, the physical absence of the researcher may also have reduced the pressure on the participants (Groves, 1990) to only report the positive aspects of their experience of using the self-help coping leaflet draft thereby minimising the Hawthorne effect (Payne & Payne, 2004) to some extent. For the final study there was no face to face or telephonic contact with the research participants, which potentially minimised this observer effect.

The approach of triangulation has also been known to overcome the Hawthorne effect and to strengthen findings (Brynman, 2003); the present study has used this approach which gives it an edge to be able to compare and cross check findings. However, it is improbable to entirely remove the researcher's influence over the participants ((Adler & Adler, 1987), yet there are ways that such effects can be diminished.

The researcher-participant relationship: The relation between researcher(s) and researched has been a recurrent concern in qualitative studies. The privileged position of the researcher vis a` vis the researched creates an inherent power imbalance and ethical concerns. This relationship between the researcher and the researched has the potential to impact the entire process of engagement, data collection and dissemination of findings (Berger & Malkinson,2000). However, it has been simultaneously emphasized that qualitative research has "…a common epistemological ground: the researcher determination to minimize the distance and separateness of researcher-participant relationships," (Karnieli-Miller, Strier, and Pessach; 2009, p. 279). Importantly, it is also argued that participants bring their own agenda to the research situation and hence it is not necessarily the sole privilege of the researcher to have all powers in the research situation (Karnieli-Miller et al., 2009). The present study held a common aim of diminishing the distance between the researcher and the researched, and creating an anti-authoritative researcher–researched relationship (Råheim et al., 2016). The researcher at no point conveyed to the participants that she was any expert in the field but reiterated at various points the importance of their opinion and how these can help to meet the purpose of this research study. The participants were briefed about the study aims, methods and what the objectives were so they may be aware of the importance of their opinion in this research.

For the first study of this thesis the participants were explained the importance of this research and that how their individual experiences may add to the understanding of parenting a child with a developmental disability as a whole. The interviews were planned and conducted in a way that the participants do not feel intimidated at any point; and realise the value of their contribution. For the second study of this thesis, the researcher had met the participants face to face in an informal group setting and there was a risk that the participants may try to appease the researcher when asked about the credibility of the self-help coping leaflet. The potential participants were hence requested by the researcher to be as judgemental about the leaflet as they could be, the researcher also informed them during the meeting, the importance of their feedback and suggestions and how this would impact the final content and format of the leaflet. Before the interviews, the participants were reminded of how important their feedback was for the further developmental of this leaflet. During the interviews the participants were gently probed for further suggestions for improvement, so they may get a chance to talk about the limitations or drawbacks of the leaflet.

The issue of anxiety or distress: The first two studies of this thesis are qualitative in nature; the first study aims to gain in-depth understanding of the lives of parents in regards to their caring roles and hence probing in nature. It was known to the researcher from the outset that the characteristics of an in-depth qualitative interview may provoke anxiety or distress in the participants (Richards & Schwartz, 2002) therefore measures were taken to deal with this appropriately if this situation occurred. This potential for distress was minimised by the researcher being clear about her role and boundaries in asking for information and by ensuring that appropriate support is available to the participants if the need be. The participants were given the option of being put in touch with a qualified counsellor if they feel overwhelmed or distressed by taking part in the interview. They were also reminded of not answering a question if they felt uncomfortable with sharing that information.

The principle of trust: The principle of trustworthiness is very relevant in qualitative research as the researcher establishes a certain relationship with the participant where one side with greater power or influence accepts responsibility to act in the other's interest (Haverkamp, 2005). For the present research, building and maintaining trust were considered paramount; all the participants in the research were given relevant information about the study, its aims and objectives (Study information sheet). There was no deception used in this study and the participants were given the contact details of the researcher and her supervisor in case they needed any further clarification about any aspect of the study.

Obligation towards research: The ethical principles of psychological studies state researchers' obligation to ensure that the research has no deleterious effects on participants because research cannot be assumed to be neutral or benign for everybody (APA, 1982; BPS, 2014; Bussell et. al., 1995). For the first qualitative study the participants were informed about their right to withdraw or not to answer a question if they feel uncomfortable about the matter being discussed. For the second study, the researcher explained to them beforehand that the study would entail the use of a self-help coping leaflet, it was however clarified that the participants should not feel obliged or feel under pressure to use it if they cannot or if they do not wish to use it. In the instructions (Appendix B.5) given alongside the leaflet the participants were informed that they did not have an obligation to use all the mentioned strategies but only the ones they felt appropriate for them. This was an important issue to address so the participants may not feel obliged to use the leaflet and are not overwhelmed by this research.

CHAPTER 5

Study One: An Interpretative Phenomenological Analysis: Exploring the stressors experienced and coping mechanisms used by parents raising a child with a developmental disability.

This chapter reports the first study of this thesis, a qualitative study designed to explore parents' experiences of raising a child with a developmental disability and to integrate it with the psychological theory of stress and coping. The theoretical foundations and epistemological groundings for this study have been explained in Chapters Three and Four. This chapter builds on that epistemology and outlines the particular steps in the analysis, providing an explanation of how themes were identified, named, and grouped in order to present a clear picture of how the participants experienced and made sense of their parental role.

Based upon the ABCX (Hill, 1958), Double ABCX model of family stress (McCubbin & Patterson, 1983) and the stress and coping theory (Lazarus & Folkman, 1984) and evidence discussed in the previous chapters (Chapters Two and Three) it is clear that being in a situation of having to care for a child with a developmental disability clearly has huge personal consequences for the parents. However, despite the stress and struggles faced by parents on a fairly regular basis (Oelofsen & Richardson, 2006; Hastings et al., 2005; Hastings; 2003) evidence shows that many parents do adapt to the challenges faced successfully using a number of coping techniques (Gerstein et al. 2009; Lai et al., 2015). Studies indicate that the coping mechanisms these parents may use may vary from individual to individual (Hastings & Johnson, 2001; Dabrowska & Pisula; 2010), for example, there may be differences in their interpretation of the crisis event (Lazarus, 1991) or the family's sources of support or family structure (Bailey & Smith, 2000). Therefore, the same crisis (having a child with a disability) may provoke a different level of stress (very high or moderate or low) and initiate the use of a different set of coping strategies (active or passive, emotional or problem focussed) in different families. The purpose of this study was thus to integrate these differences in parents' experiences with psychological theory and give the parents a chance to represent their voices in the research arena to contribute towards developing future interventions and recommendations.

Reconsidering the review of literature, the parents' experiences of raising a child with a developmental disability can be varied, with multi-factorial interactions within the environmental, social and psychological realms. Quantitative methodologies often overlook these individual experiences. In order to see how caring for a child with a disability affects a parent's life and how each parent deals with this situation in their unique environment, this subject had to be addressed from the perspective of the parents themselves who undergo this experience. The proposed research question hence was conceptualized within this realm of knowledge - within a methodological framework situated in a first-person perspective for a systematic examination of experience (Finlay, 2008) using the 'interpretative phenomenological analysis' (IPA) approach (e.g. Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009). An explanation and rationale for using this approach has been provided in Chapter Four.

Study Aims

The aim of this study was, to understand the differences in the perception of stress and coping in parents, to gain a 'parent centred perspective' of this phenomena. It was intended that findings from this qualitative study would inform the PhD in two important ways. Firstly, it would identify the role of parenting a child with developmental disability and how this affects the perception of stress amongst parents. Secondly, it was hoped that the understanding gained from the interview study would aid in design of an appropriate intervention by enabling key coping techniques used by parents to be identified. The specific objectives of the study were:

To identify the key challenges and stressors faced by parents of children with developmental disabilities at various life stages.

To identify the range of coping strategies used to overcome parenting stress.

Design

The intention of the research question was to explore the experience of parenting a child with a disability, therefore, meaning was considered central (Kvale, 1996). Hence, to understand the content and complexity of what is being said a qualitative interview approach was used to understand the participants' perspectives to defining phenomena they have experienced. As suggested previously (Chapter Four) the Interpretative Phenomenological Analysis' (IPA, Smith, 1996) is a specific hermeneutic approach committed to exploring how people make sense of experiences in their lives (Smith, et al., 2009). It involves understanding what it is like for people to be in their life world. Epistemologically, researchers using IPA engage in a reflective focus on participants' lived experiences and how they make sense of these (Smith et al., 2009). The aim of this study was to understand the subjectivity of the experience of parenting a child with a developmental disability, and to identify themes which could voice the parents' inner most feelings of this experience and focus on attaining a detailed understanding of those personal experiences (Willig, 2001). In order to gain a deeper comprehension of the day to day stress encountered and coping mechanisms used by parents of children with disabilities, the IPA approach was considered most consistent and compatible and to summarise from the previous chapter, chosen for the following reasons:

Firstly, IPA is consistent with the research aims, in that it is committed to the examination of how people make sense of their major life experiences (Smith et al. 2009); this study aims to find out how parents perceive or make sense of their role as carers for a child diagnosed with a developmental disability. For the present study it was intended to gain, an "insider's perspective" (Conrad, 1987) therefore the study adopted a phenomenological approach to understand the depth in the parents experiences of stress and coping while caring for a child with a disability. IPA involves the detailed examination of the participants' life worlds and it bestows the researcher to identify and understand the significance of the experience which the participant has experienced. The phenomenological approach of the IPA also focusses on exploring experience in its own terms rather than attempting to reduce it to predefined or overly abstract categories (Smith et al. 2009). Therefore, it was considered most appropriate to use with parents of children with developmental disabilities as it provides differing perspectives on a similar phenomenon (parenting disabled children) from those who are experiencing it rather than being governed by predetermined notions in existing research (Shaw, 2001).

Secondly, IPA is idiographic in nature, in that it is concerned with the particular, with revealing something about the experience of each of the individuals involved, and being able to say something in detail about the participant group. IPA aims at investigating in detail certain lived experiences of a small number of individuals rather than generalising notions for large populations so the researcher can draw inferences by learning from those who are experiencing it rather than from pre-existing theories (Shaw, 2001). The present study aims to understand the phenomena of stress and coping from the point of view of the parents who are caring for their child with a disability, in order to then be able to make more general claims for a similar population cautiously, as Smith (2004; pg 42) cites Warnock (1987) as having made the point that “delving deeper into the particular also takes us closer to the universal”.

Also, Smith and Osborn (2008) advocate that IPA is a methodology which is markedly proficient for analysing complexity, novelty or process. Many issues that arise in the domain of parenting children with developmental disabilities are complex, dynamic and difficult and IPA gives the opportunity of engaging with these issues (Chapman & Smith, 2002). IPA has also been considered particularly useful in areas where issues arising are relatively unconventional and where they may raise potentially sensitive and affective responses from the participants (Chapman & Smith, 2002). IPA, therefore, fits well with the aim of this study which is to explore the complex nature and process of stress and coping flexibly and in detail in parents of children with developmental disabilities.

Limitations of IPA

As discussed in the section above and in Chapter Four, IPA aims at gaining an insider's perspective which is achieved through listening to and analysing the language participants use to describe their lived experiences. The IPA hence essentially relies upon how well an individual or participant can articulate rather complex emotions, feelings and thoughts. If individuals are not accustomed to conveying their inner most feelings and intricate details of their experience it can be challenging experience for them, as Jaeger & Rosnow (1988) elaborate that there are limitations of language which may create boundaries to sharing experiences. Smith et al (2009) additionally argue that "our interpretations of experience are always shaped, limited and enabled by, language" (p. 194) and this poses another dilemma which is, can words fully communicate individual perceptions comprehensively?

Most methodological approaches, such as narrative analysis or discourse analysis justify the analysis of language in terms of understanding how a participant creates or constructs their reality. Willig (2013) puts forward the point that, researchers can only gain an understanding of how people talk about their experiences rather than an understanding of the actual experience through language. Smith and Osborn (2008) and Smith et al., (2009,) per contra contend that there is in fact a direct relationship between how people talk about their experiences, thoughts and feelings surrounding these. The present research acknowledges the critique outlined by Willig (2013) but affirms that language can be a powerful medium which can help the researcher to understand how the participants experience a certain phenomenon and how they describe their lived reality.

Another limitation of IPA is that it does not attempt to explain why people experience certain phenomena in certain ways. Willig (2013), argues that this is a potential drawback as the lack of this explanation can restrict the understanding of a phenomena. Brocki & Wearden, (2006) further this argument by asserting that any interpretations that a researcher makes are constrained by the researcher's ability to interpret, reflect and make sense of the data. This assertion is concerning for all novice researchers but relevant training, the use of comprehensive guidelines and discussions regarding the interpretative process (for example, Smith, 2004) can help the researcher to overcome this limitation. For this study, the researcher also considered the context of each participant as it influenced their recounting of social experiences with the intention of considering the researcher's own interpretations as they related to existing literature. In this way, the IPA study had the potential to fill a gap in knowledge about the lived experiences of parents caring for a child with a developmental disability.

Method

Ethical Considerations

This research study aims at a particularly sensitive area of inquiry and therefore a detailed consideration was given to ensure that this research study was ethically sound. The research was conducted with regard to the Code of Human Research Ethics (BPS, 2010) and was granted ethical approval by the University of Wales Trinity Saint David Research Ethics Committee (April 2012). Consideration of ethical issues were undertaken prior to the start of the research and the ethical plan was revisited before moving into each active stage of research. Establishing that the research process was underpinned by a respectful and trustworthy approach was of paramount importance during design and implementation, and particular regard was paid to ensuring consent, confidentiality and the reduction of potential for harm. Accordingly, ethical considerations were an integral part in the study design and effort was made to ensure that participants were in no worse a situation after the study than when they entered it and hopefully exited the study in a better position through the reflective process. Finally, in order to ensure trustworthiness, guidelines for qualitative research recommended by Yardley (2000; 2008) were considered alongside the research process (please refer to Chapter Four for an in-depth discussion of these).

The study procedures described below were given full ethical approval by the University of Wales Trinity Saint David Research Ethics Committee (April 2012). Through this process, the research design and documentation (including letters of invitation, information sheets, consent forms, interview schedule), were endorsed.

All the participants in this study had the necessary competence to give consent to participate and were fully and truthfully informed about all aspects of the study through the use of a Study Information Sheet (Appendix A.1). The potential participants were given time to process and reflect on this information before agreeing to participate in the study. Written consent was obtained before each interview and as part of this process, the participants had to indicate that they had read the Study Information Sheet, understood that their participation was voluntary and understood that their responses would be anonymised (Appendix A.2). They were also given the opportunity to ask any additional questions before agreeing to take part. Although written consent was obtained at a one off time, ensuring continual consent was an ongoing process involved remaining sensitive to the participants verbal and non-verbal behaviour. The participants were informed on the Study Information Sheet that they were free to withdraw at any time without explanation and this was emphasised before the start of each interview.

To maintain confidentiality, participants' names and identifying information were changed for data presentation. The study adhered to the British Psychological Society guidelines in terms of general respect of participants, standard of privacy and confidentiality. The data collected was handled in an anonymous form and this involved giving individual participants a number instead of using their name or initials. They were informed that the interviews would be audio-recorded to aid with analysis and that the audio recordings and transcriptions would be anonymised, securely stored and then destroyed in due course of time.

Data (interview recordings) were deleted from the recorder within 48 hours of the interview taking place once they were uploaded to a password protected computer on the University server. Only the researcher and her supervisors had access to this data. Once transcribed and approved by the study supervisor the recordings were deleted permanently from the computer. Whilst transcribing the interviews, personal information was removed and names of the participants were coded/changed to maintain anonymity. Other names used in the interview such as that of the child were changed too. Information contained within the Study Information Sheet and the consent form ensured that the participants were aware of what was intended to do with the data after it had been anonymised. After completion of the study no participant data were able to be identified to the individual. Consent forms were stored separately from all data.

There was a risk that taking part in the study may be potentially distressing to the participants. To minimise this potential, the participants were told in advance roughly how long the interview should take, given the option of when and where they would like the interview to take place, assured that the research was aiming to increase understanding and not focusing on judging or criticising. Participants were made aware that they could ask for a break at any time, and had the right not to answer particular questions if they did not want to. They were also informed that could withdraw from the study at any time, without having to give a reason for doing so. The participants were also given an option of making contact with a stress management helpline if they experienced increased stress because of taking part in the study. It is also important to recognise that along with the potential for harm it is important to recognise that there was also the potential for the participants to enjoy the experience of being listened to and sharing their views.

Due to the sensitivity of the topics discussed the researcher was at a potential risk of distress as well, the protocol for the researcher in this situation was to report this to the supervisory team and if the need be, make contact with a qualified counsellor who is a collaborator on this study.

Participants

The topic of this research is quite specific and therefore the potential sample population is relatively small. It has been acknowledged that when this is the case, homogeneity is achieved by sampling a group of people who share and can therefore offer insight into a particular experience (Smith et al, 2009; Langdridge, 2007). The participants for the present study were parents of children diagnosed with any developmental disability, aged up to 16 years and living in the UK. They were treated as a homogeneous group who share the experience of having the responsibility of caring for a child with a developmental disability.

Inclusion and exclusion criteria: Participants were deemed suitable for participation if they were:

A parent with a child with a diagnosis of a developmental disability.

If the child was aged 0-16 years.

A parent who was able to give informed consent.

Participants were deemed unsuitable if they were:

A parent who could not communicate in the mode of English as the interviews were conducted in the medium of English.

Recruitment procedure:

The method of sampling for this study was purposeful in order to recruit participants who share the common experience of raising a child with a developmental disability. The study was advertised through the social network page of Cerebra, (a charity for children with neurological problems) and by emailing various parent support groups within the Swansea area. The researcher was contacted by the potential participants via email to express their willingness to take part in the research. These potential participants were then sent a copy of the study information sheets and were asked to read this (Appendix A.1; A.2 and A.3 for study materials) before deciding whether or not to take part in the study and were given the opportunity to ask questions about it. Only those providing written consent after going through the study information sheet were included in the study. After accounting for the eligibility criteria, the present study had a final purposive sample of eight mothers who had children aged between 2 and 16 years diagnosed with a developmental disability. Three mothers lived locally in the Swansea area, whereas the others were from different parts of the United Kingdom. In terms of the number of participants in qualitative studies, Reid et al., (2005) propose that the interpretative analysis challenges the traditional linear relationship between the number of participants and the value of research. Hefferon & GilRodriguez (2011), further add to this argument suggesting that “more is not always more” (p. 756). As IPA is idiographic in nature, small sample sizes are considered appropriate as they allow for the in-depth analysis of individual cases and experiences. Smith et al (2009), highlight that students undertaking professional doctorates usually engage in four to 10 interviews and for this reason a sample size of eight appears to be appropriate for the aims of this thesis.

Data collection

According to Smith et al., (2009), IPA is best suited to a data collection method that invites “participants to offer a rich, detailed, first-person account of their experiences” and “facilitate the elicitation of stories, thoughts and feelings about the target phenomenon” (p. 56). There were certain persuasive reasons for using interviewing as the primary data source for this study. Qualitative interviewing is considered appropriate when “studying people’s understanding of the meaning in their lived world” (Kvale, 1996, p. 105). Besides, qualitative interviews also help to find out what is in and on someone else’s mind, as Patton (1987) suggests “We interview people to find out from them those things we can’t observe” (Patton, 1987, p. 196). Qualitative interviews also result in thick descriptions of the subject being studied that enable readers to make decisions about transferability of study results (Merriam, 2002). Finally, interviews allow for triangulation of information obtained from other sources and, thus, increase the credibility of study findings (Merriam, 2002; Thurmond, 2001; Stake, 1995).

There are various methods of data collection used for gathering in-depth information from participants such as focus groups, face to face interviews, telephone interviews and computer mediated communications. Although considered as being useful for gathering quality information (Krueger, 1996) focus groups were deliberately not chosen for this in-depth study as even though group interaction may facilitate an exchange of ideas and information, some members may deliberately fail to exchange all information. This may partly be due to the nature and sensitivity of the content and hence the data may focus only on shared information (Levine and Moreland, 1995). For this study, the nature of information was considered personal and sensitive and therefore one to one interviews were considered a better option.

All the participants were given an option to be interviewed face to face by the researcher at a date, time and place of convenience to them but only two of the eight mothers agreed to be interviewed face to face. Therefore, the remaining six interviews were conducted on the telephone at a mutually agreed time and day. The use of telephones for the interviews (six) was in line with the wishes of the participants, despite traditionalists viewing the use of the telephone in qualitative interviews as an inferior data collection instrument (e.g. Gillham, 2005; Legard et al., 2003; Shuy, 2003). These researchers caution that such interactions lack a contextual naturalness (Shuy, 2003; Sturges & Hanrahan, 2004; Sweet, 2002), however, these claims have not been supported by empirical evidence and qualitative researchers who have used and compared the telephone to the face-to-face mode of interviewing techniques (Vogl, 2013; Irvine, Drew, & Sainsbury,2012). Although concerns about the more unnatural nature of telephone interview conversations are commonly raised, there is also recognition that in many cultures today, people are well used to communicating by telephone both informally (e.g. Gillham, 2005) and in formal settings. Studies have shown that interview participants when given the option of face-to-face and telephone interviews have voluntarily selected the telephone as their preferred interview mode (Sturges & Hanrahan, 2004; Holt, 2010).

Researchers also argue that face-to-face interviews’ have a distinct advantage in providing ‘social cues’ such as voice, intonation and body language which may provide a lot of extra information that can be added to the verbal answer of the interviewee (Opdenakker ,2006; Stephens, 2007). However, it can be argued that the importance of these non-verbal cues may vary depending on the research objectives (Novick 2008), for the present research it was not considered essential to record the non-verbal cues for analysis and so the participants preferred method of interview was given priority. Some studies have also revealed that there may be no difference what so ever in the number of responses to questions asked or differences in the nature and depth of these responses across interview modes (e.g . Sturges & Hanrahan ,2004; Stephens, 2007; Trier-Bieniek, 2012). Importantly, Trier-Bieniek, (2012), points out that there is never a guarantee of a researcher being able to build rapport in a face-to-face interview.

Also, as this specific group of participants have a high burden of care taking responsibilities and most of them could not commit to a face to face interview and this was acknowledged by the researcher. As most potential participants in this study preferred telephone interviews, it was hoped that being interviewed on the phone may enable them to disclose sensitive information more freely (Hopper, 1992).

Semi structured interviews: Semi-structured interviewing appears to be the most widely adopted method for IPA researchers (Reid et al, 2005) and was used in this instance for data collection. The strength of this method of data collection is that it grants the participant an opportunity to speak freely and openly about topics which they feel are pertinent, whilst also ensuring that areas relevant to the research question are covered (Smith et al, 2009). A semi-structured interview schedule was devised beforehand as a flexible tool to help guide the discussions in the interviews following the procedure described by Smith (1995). This schedule acted as a guide for the researcher and outlined all areas of interest and mapped the possible ways in which the interview may proceed. Questions that are more descriptive were placed at the start of the interview to help set the scene and questions that are more sensitive were saved until participants had become more comfortable with the discussion. Additional prompting and probing questions were devised to encourage to talk in more depth and elaborate on points further. A semi-structured schedule (Appendix A.4) was devised following a review of literature in relevant past research focusing on stress in parenting children with various developmental disabilities.

The following areas were included:

Stress in parenting a child with a developmental disability

Stressors or challenges as a result of key developmental stages

Coping mechanisms employed

In order to confirm the general appropriateness of the devised schedule, one pilot interview and one practice interview was conducted. The schedule was hence developed, refined and updated through reflecting with peers, and through the use of the pilot study. The schedule therefore underwent minor re-drafting throughout these processes.

All the interviews for the present study were arranged at a day and time convenient for the participant. In accordance with the British Psychological Society’s Code of Ethics and Conduct, the participants were given an opportunity to ask any questions or address any concerns they had about the study from the outset, they were also advised that they could withdraw from the study at any time, and can refuse to answer any question they feel uncomfortable in answering. The researcher also verbally reaffirmed consent before the start of the interview. All the interviews were audio-recorded and transcribed to aid with analysis. Recorded data was transcribed within 24-72 hours of recording.

Data Analysis

Each interview was transcribed within 24-72 hours of recording. In order to maintain the anonymity of the participants and their children (references to whom have been made by name at various points in the interview) all identifying information was removed or changed.

Following the transcribing, each transcript was subjected to a detailed systematic qualitative analysis using the Interpretative Phenomenological Analysis approach. As the IPA does not outline a prescriptive methodology (Smith & Osborn, 2003) and lays emphasis on flexibility, all interviews were analysed individually following general principles underpinning this process originally formulated by Smith, Flowers and Larkin (2009, p.79-175) and enhanced with suggestions by Larkin (2015) and Dahlberg et al., (2008). As suggested by Larkin et al., (2006) there are two aims in analyzing data in an IPA study. The first of which is to try to understand and describe what the world of the participant is “like” and the second being interpretative and intended to provide a “critical and conceptual commentary” (Larkin et al, 2006, p. 104) on how the participants made sense of their experiences. The difference between analysing data in an IPA study and other qualitative approaches is that the IPA focuses on the participants’ process of making sense of their experiences as much as it does on the experiences themselves. Smith et al (2009) outline a number of stages involved in data analysis and these were used flexibly to help guide the process. The developing analysis involved moving from a focus on the individual to a more shared understanding; and, from a descriptive level to an interpretative one (Smith et al, 2009). The following section presents a description of the process involved with each step in the analysis. These have been originally formulated by Smith, Flowers and Larkin (2009, p.79-175).

Step One: Following transcription of all the interviews, the researcher familiarised herself with the text. A case-by-case analysis involved active engagement with the data, with the researcher now re-engaged with her fore-understanding. Each transcript was read and re-read many times to acquire an extensive understanding of the nature of the participant’s account.

Step Two: Each script was then read again carefully, maintaining an open mind, becoming more familiar with content and getting a ‘feel’ for data. This stage involved initial noting to examine the content on a very exploratory level. The text was annotated with comments, descriptive labels and initial thoughts while reading.

Step Three: According to the IPA’s idiographic commitment, each interview was first analysed in-depth individually (Smith et al. 2009). Initial annotations were made in one margin, with exploratory comments describing initial thoughts about the content, language and more conceptual, interrogative comments (Smith et al. 2009). Each transcript was read and re-read many times to acquire an extensive understanding of the nature of the participant's account. The text was annotated with comments, descriptive labels and initial thoughts while reading. Such initial noting included observations and mainly descriptive accounts of the meaning to the participant, e.g., perceiving how stressful was their caring role. At the end of this stage transcripts were read more carefully and reflectively, this time whilst listening to the soundtrack, to merge the spoken dialogue with the written word. This process drew attention to how, through translation, some simple, short quotations lost the powerful impression during the interview and allowed these to be captured.

Step Four: Each transcript was then re-read in full and emergent themes were recorded on the text using keywords. Concise statements (emergent themes) were developed to capture and reflect understanding.

The emergent themes were labelled and listed chronologically and then moved around to form clusters of related themes. Each transcript was then re-read in full and emergent themes were recorded on the text using keywords. These were typically expressed at a theoretical level rather than in the participants own words.

As more than one IPA transcript was analysed, the researcher had the option of either using the super-ordinate themes from the first case to identify further examples within subsequent cases [whilst checking for new themes] or starting the whole process again, with each subsequent case producing lists of themes. The researcher adopted the recommendation of Smith, Flowers and Larkin (2009, p.100) to use the latter approach, ensuring that analysis of each transcript was complete before moving on, treating each interview as a separate case-by-case analysis and justifying each participant's individuality by bracketing concepts from prior case analysis. Accordingly, analysis remained committed to IPA's dedication to ideography, as analysis moved systematically from the particular to the shared.

Step Five: The emergent themes within, across, and between contributions were checked again for connections, convergence, and divergence (Smith, Flowers and Larkin, 2009) with firm master themes now emerging.

These were then summarized and organized to determine their interrelationships and identify emerging subordinate themes. This stage introduced structure into the analysis. Emergent themes were drawn together by identifying common links between them using the concepts of abstraction (similar themes brought together), subsumption (emergent theme becomes subordinate theme), numeration (frequency in which theme is supported signifies importance) and function (what function it serves). This produced a number of subordinate themes with related emergent themes. Subsequently, connections were established between themes so that a coherent and organized thematic account of each case could be produced.

The remaining transcripts were then analysed using stages 1-4. Each case was approached in its own right to allow new themes to be developed. All the subordinate themes generated after the analysis were approved by the study supervisor before the next step of amalgamation.

Step Six: A list of themes was then amalgamated for all transcripts and tested against the account of each participant. This stage involved looking for patterns across cases. This was achieved by drawing up a list of themes for the group, and clustering these into master (superordinate) themes representing shared higher-order qualities. The superordinate themes were then checked against the transcripts to ensure that they remained grounded in the data. These themes were ordered into a comprehensive description so that they created a coherent narrative of the participant's experience, with theory and prior knowledge now an acknowledged interpretative tool. Finally, the superordinate themes were translated into a narrative account where the themes were outlined, exemplified and illustrated with verbatim extracts from the scripts (Chapman & Smith, 2002). The master table of themes for the group is shown in a table (See Appendix D.1).

Results

The following section presents the five main superordinate themes which emerged from the Interpretative Phenomenological Analysis, these themes describe how the mothers in the present study view and experience their caring role. Each theme will be discussed in turn and illustrated with examples from the interview transcripts. Names of participants have been changed in order to preserve anonymity and confidentiality.

The first superordinate theme, playing a special role, explores the emotions associated with caring for a disabled child. It is divided into three subordinate themes: the paradox of love and hate, the feeling of being the sole provider, and taking a different path in parenting.

The second superordinate theme, enhancing inner strength and resilience, explores the experience of growth whilst providing care. This has been divided into two subordinate themes: developing the self, and constant feeling of obligation.

The third superordinate theme, private burden private coping, relates to how these mothers cope with their situation on a day to day basis. This has been divided into four subordinate themes: taking a miss, learning to deal better, having guilt free moments, and combining the best of all.

The fourth superordinate theme, discontentment and isolation, explores maternal perceptions of hardships and social exclusion, including feelings of solitary burden and falling in a circle of systems.

The final superordinate theme, positive outlook and perception, explores the positive influence of caring for a child with a developmental disability. This has been divided into two subordinate themes related to transforming the self and changing perceptions.

The quotes were selected to signify a range of outlooks within each theme to capture the uniqueness of each individual account.

(i) Playing a special role: This superordinate theme captured the idea that the participants' found themselves in a continuous internal struggle of emotions, often oscillating between the feelings of love and hate towards their role as a carer for their child with a disability. Participants put forward the idea that they experienced a lack of certainty regarding their emotions based on the immense pressures of parenting a child with atypical needs.

The Love and Hate Paradox: The interpretation of the parents' experience of caring for a child with a developmental disability took shape in the light of the major themes of 'love' and 'hate'. In what was a clearly challenging paradox, the parents in this study accepted and loved their caring role, but also hated it because of the enormity of tasks associated with it and the barrier it posed to lead a ‘normal life’.

Carole: “Sometimes I love it; sometimes I hate it… I get very frustrated. Its hard….

Neala, gave an account that conveyed that having a child with a special condition has made her life very different from the normal and her role as a parent is affecting her emotional and physiological capabilities. However, it is important to note here that the parent (Neala) endows a positive attitude towards her caring responsibility despite of the immense efforts she has to put in to take care of her daughter, as highlighted in the following text:

Neala: “Life has changed so dramatically, but yeah, yeah, it is rewarding. I would say it is very tiring as well, draining me physically and emotionally at times. However, I do enjoy the responsibility”

Lynn’s account of looking after her son has been paralleled to a ‘struggle’ by her, which she has to go through every day which is suggestive that her experience of being a carer has been a daily challenge which she has to go through every day. Lynn’s account of her caring duties were mostly pervasively negative, however, she insisted that despite this she loved her son again highlighting the paradox of love and hate of being a carer.

Lynn: “My experience of caring for him, it’s a struggle getting through everyday really, I mean I love him to bits but it’s very stressful looking after him, … it makes me feel weak and tired. It can make you both, both stronger and weaker at the same time cos you need the strength to get through the day but then at the same time it can be very exhausting.”

The feeling of being the 'Constant Provider' : This theme addresses the participants' accounts of being the solitary provider in meeting the child's day to day needs. It also highlights to a large extent that the parents hardly have any time for themselves depending on the care needs of their child, which they have to meet solely themselves (all mothers in this study).

As the excerpt from the interview below explains, caring responsibilities for all the parents were ceaseless, as the parents described their feelings about their caring role they painted a picture of a task that is relentless, exhaustive and often overwhelming.

Judith: "…I get very frustrated, tired both physically and mentally…He's dependent in the fact that he needs me to do basics for him, cooking, washing just even taking stuff out of his room because is a disorganized one. He'll use something and say where it is, cleaning and tidying up even though I tried various ways to make him see the benefit of that and he needs me to get him to college because he wont go another way and he wont even go with a taxi driver…"

It was also suggested that the diagnosis of the child dictate the caring duties to a very large extent, which depending upon the diagnosis can be very exhaustive, as Kate explained:

Kate: "…it is not just one condition that we are dealing with… she is dependent on me and her gran in almost every way….(long pause). From getting her up and ready for the day, sending her to part time special school, feeding her (sigh) the list goes on. Has this answered your question? … she can manage a few things on her own but we need to keep an eye as she cannot see and perceive shapes and *depths very accurately. Its her condition that directs every aspect of her life in a way, in a certain way".*

In very simple terms Neala puts the crux of the situation for all the parents in her situation:

"The caring responsibilities are really, well they are really constant"…

Susan also in a matter-of-fact way explained:

"We are on duty 24 hours a day 7 days a week, we cant leave J with other people or go out or do any other things which normally do by the time he reaches the stage I am constantly having to give up work and then trying to find another job and then I have to give it up again".

The content of her description suggests that by now she has become accustomed to her routine of providing around the clock care and accepting the fact that her caring duties may never allow her to lead a typical social and work life.

Taking a different path in parenting: All the parents interviewed suggested that parenting was different for them due the atypical needs their children had. The parents acknowledged that the behaviour or disability of the child also affected their perception of their caring role, for example, a child who is highly dependent on the parents due to his or her condition would result in more stress, exhaustion or fatigue in the parents.

Judith: "…he reaches later the mental levels, physically he's reached puberty same time as other people. Mentally and socially and maturity [wise] he is behind his peer group and coupled with his strengths it's quite a difficult combination"

Lynn's account is similar to Judith's in the sense that her son also seems to lack the intellectual capacity to be able to make sound judgements but is physically able to do things that his typically developing peers would do thereby putting himself in a position of threat and causing much stress to his mother:

Lynn: "…when I get him out of the push chair he just runs off, he won't respond to his name, he's got no sense of danger so he would run onto a moving car or he would, he would run towards the river or think it's a puddle".

Judith: "… as he is, he wouldn't accept help sort of thing I've still got that problem of getting him up every day, going to school, but now he can dress himself up, I still got the problem of getting him through a proper meal, putting his stuff out for washing…We had a problem with him, not putting on clothes as I say and not washing a certain time so he's now quite badly… he will now have showers but again its on his terms, two o clock in the morning or something".

As demonstrated in the above quote, Judith has struggled with various kinds of problems over time but cannot see an end to them anywhere near due to the behavioural problems her son suffers from.

Another emergent theme sub theme was an increased vulnerability is a characteristic associated with disability; a fear of their children being abused has been a repeated theme from parents who have adolescents with a disability. The present study echoed similar findings of vulnerability being a stressor for parents:

Neala: " The one thing that I worry about most is her vulnerability as she is growing, her mental abilities are not in line with her biological age and that is what worries me. She fails, well, she can't just can't differentiate between friends and *people pretending to be friends, so I guess that is what my worry is really you know".*

Jane: "… he obviously can't go out with other children because his social skills are so poor".

The increasing physical strength was also quoted as a stressor by the parents in the present study, speaking about how her caring respponsibilities are changing with her growing son one of the parents' articulated

Lynn: "… he is very strong and he is only little, still got an incredible strength, when he gets bigger so that worries me, how will I manage when he gets older… I think its *just like the fact that he'll be bigger as well, worries me and obviously stronger and because he gets very angry and frustrated at the moment that's what worries me I suppose he might break things or be angry towards me, that worries me".*

Maria suggested that she cannot adequately cope with the growing physical strength of her son which was a 'stressor' for her as she explained:

Maria: "I mean you know I still have to do you know the basic feeding , clothing etc. but where he is getting stronger, he is more physical, I mean he has hit me and what have you, so therefore what I have done, I have actually contacted the police when he has hit me because I will not up with that you know, and he has spent one night in a jail in the cell…".

(ii) Enhancing Inner Strength and Resilience: This superordinate theme addresses the participants' accounts of experiencing 'growth' and realising 'potential' as a result of being able to accomplish their role as parent successfully.

The theme includes the relationship between growing stronger and being more efficient in the parenting role.

Developing the Self: This theme draws upon the various ways through which participants describe the process of acquiring strengths for the well-being of their child. As suggested in the extracts above, caring for a disabled child can be very exhaustive; all participants in their interviews articulated that they had recognised new strengths in them as a result of caring for their child.

Jane: "Ya, I suppose in a way it has made me, made me stronger as a person… Honestly, it has made me a much stronger person than I ever was, having P has made me identify strengths I never knew I had. I feel I am very independent, very strong now. I have to be strong for her and for myself".

It was apparent during the course of the interviews that this strength across all cases was not inherent and was acquired as and when the need was felt, as Judith suggests:

"… I find that I can fight for him, whereas I wouldn't fight for me. I find that in myself strengths that I didn't know I had, it took me six months and I managed to get him statemented when they said they don't do statements [social services department]. …he wanted to move in her bedroom, you know, but the department don't like it because his bedroom is pink, pink! What harm is it to him to have a pink bedroom?"

Constant feeling of obligation: The feeling of being obliged towards performing a duty ran ceaselessly through the interviews. The parents' accounts suggested that felt they had an obligation to perform their role ceaselessly whilst depriving themselves of various personal and social opportunities.

A recurrent theme which ran across all interviews was that of a lack of choice, that these parents had, all the participants stated regularly during their interviews that they had ‘no choice’ in relation the caring role they had.

Lynn: “... it does make me feel very stressed but I have to carry on because there is no one else who will look after him”.

Jane: “Yes, it is very stressful but I think you know, if I don’t do this who else will?”

The parents indicated subtly that they do not have much option regarding their role as carers, they had to perform this duty ceaselessly without having options of a break or respite. The parents’ comments about the lack of choice creates ambivalent and equivocal feelings that are suggestive of the paradox of ‘love and hate’ mentioned earlier.

Julia: “... when I am exhausted I feel that I cant cope very well at all and I am quite tearful and snappy and not much fun to be around and, but I do find that once I have had a break then I feel better again, I kind of recharge my batteries and I am ready to go again and so in that prospective it’s made me feel a bit weaker but on the whole I would say it’s made me a stronger person and I’ve had people say to me “I don’t know how you cope?” ; well it’s a case of having to; I don’t have a choice”.

Or as Neala puts it: *“I have to be strong, for her and for myself... we have to face it you see”*

(iii) Private Burden=Private Coping: Even though all the parents interviewed suggested that they feel immensely isolated in playing the role of the carer of their child, they ironically also suggested that they feel the stress as a result

of the condition or diagnosis of their child is their ‘private burden’ and they have devised mechanisms to deal with the stressors they face in parenting according to their very personal circumstances. The analysis revealed that participants coped with their unique stressors in a number of different ways, individual differences in coping preferences were apparent.

Taking a ‘miss’ for a while: The participants (mothers) suggested that they sometimes found it beneficial to avoid the stressful situation at times in order to combat the stress they might face. The theme of avoiding the stressful situation in order to control intrusive worries was echoed by some of the parents during their interviews. Avoidance coping can involve person oriented responses such as seeking social diversions or task oriented responses such as engaging in distracting activities.

As Jane explained:

“… and I read, I lead a very active life, I am learning Welsh. I lead a very busy life and a very full life. I am never bored, somebody said to me are you bored? Bored! I am never bored , there is always something to do you know…”.

Jane’s account of her busy life can be examined as an effort to avoid thinking about the stressors in her caring role. Her account has an underlying implication of ‘avoidance coping’, she maintains that tries to keep herself occupied or busy all the time which indicates that she unconsciously is not getting enough time to think about the main stressor in her life which is her child’s developmental disability.

Having guilt free moments: All mothers in the study reflected on their levels of stress and mechanisms which they use to cope; various parents suggested that having some time solely for themselves gives them a deserved break. Many participants suggested that they make effort to go out for a walk, go to the gym, run or read; most parents in the present study aimed to have at least some 'me-time' to unwind and relax.

Susan: "Yes I used to be a member of a gym which I had to give up because I couldn't afford it anymore, but being able to exercise and then sit in a spa really brought a huge amount of relief, yeah.. Something like that that practically helps, so if somebody has a child, they can go and do some exercise and just sit in a spa for a while that would really help. Yeah".

As Jane suggest in the following quote having some time to unwind proves beneficial:

Jane: "My blood pressure is a bit high (jokingly) amm… I go walking actually, that's how I deal with my stress. I walk really far I've just got a new puppy whose and we walk, we walk and we walk and it helps and we talk then me and C but the walk is so (…) therapeutic for me".

Learning to deal better: As time progresses, parents suggested, they learn to deal more effectively with the problems or stressors they deal with in having to care for child with a disability. Parents explained that they found that they could deal with certain problems in a better manner if they were better equipped practically, for example, in terms of current knowledge, relevant information etc.

As Neala explains:

"… I talk about my worries with people who can help; I've had discussions with her teachers and education authorities as they make her transition plans. I have spoken to her doctors, well it's getting the right information from the right people so we may be prepared for the changes…"

Neala's account of her ways to keep abreast with relevant information is also suggestive that she has clearly accepted her situation and is trying to focus on ways which can help her to deal with the situation in a better manner rather than dwelling upon the negative aspects of having a child with a neurological disability.

During the interviews it was suggested that changes which are inevitable can be made less stressful by being somewhat prepared for in advance, as Julia explained:

Julia: "... my (name) went to secondary school in September so the transition from primary to secondary school, I was really worried about, but we planned it with the school, worked really closely with the school and they provided a lots of extra visits for him and lots of preparation so, they helped made it his new school so there were pictures, there were pictures of the new school, ... lots of preparation and thankfully it went really smoothly and he settled in really really well. But I think without that much preparation, it probably would have been a different outcome... My experience with my own children is that those bigger things that they have been prepared for, they can just accept but it's the small things like if I give him the wrong spoon then it is being launched across the room and you know it's the small things that you have not prepared for they are the ones that are difficult and they cause more stress. The big moves, the big transitions are absolutely fine because they are managed, they are prepared for".

Combining the best of all: Within Neala's account she described how she feels that she would be able to deal with her situation in a better manner if she can be given a chance to network with other individual's facing a similar problem; her account is suggestive that she aims to use mixed methods of coping which cover areas of both problem and emotion focused coping, i.e. communicating with people dealing with somewhat similar stressors can lead to ideas of resolving various practical problems related with the condition and offer emotional support by helping to identify ways of dealing with regulation of emotions related to the problem.

Neala elaborates:

> *"… It brings my mind to ease I would say, you know. I go through the internet to find information, have joined a number of forums, parent support groups, anything that I think would help really. There are times when you get very useful tips and hints and then there are times when your ideas help someone who is caring for their child. Having information, having sound researched information really helps".*

(iv) Discontentment and Isolation: This superordinate theme draws upon the common ways in which the participants report their feelings of social isolation due to being the carer of a child with a disability and their feelings of frustration and discontentment because of the lack of understanding from various professionals.

A solitary burden: Various participants suggested that they found that parenting for a child with a developmental disability has isolated them from the society to a large extent. This isolation in all cases was a result of the extra caring demands on the parents and resulted in them [parents] being not able to socialise as often as their peers would normally do making their position somewhat different in the societal set up. Susan, described how over the years she has lost her confidence in being able to socialise

Susan: "Yes, it has, changed me. … it has made me a lot stronger but less sociable, so I think, I have forgotten somehow to go out with a crowd of people and *to chat and if I am in that type of situation I don't know what to do so I just come home cause I lost all my confidence*".

Julia also described her feelings of isolation because of the different situation she was in:

Julia: "I do feel quite isolated, and I sometimes, not so much now, but sometimes would look at other families with children of a similar age and feel quite envious,.. they have that and feel quite sad that looking at what their children are achieving and then looking at mine and thinking they should be doing things and and yes, that makes you feel quite isolated".

Maria's perception was overwhelmingly of that of loneliness and isolation:

Maria: "... feel so alone and so isolated".

Payal: And this feeling of isolation have you felt it because of your son's condition, do you feel you are isolated from the rest of the society?

Maria: "Ya, totally, totally. Because from an early age as a parent of normal children just give it, it will be ok, No, it wont!"

Falling in a vicious circle of systems: The importance of formal support systems emerged as a prominent theme. These systems included family and professionals who have helped parents to cope with the experiences and challenges of raising a child with a disability. The overall experience of receiving formal support was experienced negatively by most parents as elaborated by the following excerpts:

Maria: "...the whole process again asking for an assessment, I was turned down, I appealed against it and two weeks before the hearing they said yes, you can *have an assessment they gave him another one an assessment, they gave him a statement, but a mainstream school and I knew he couldn't cope that so again I appealed and literally two days before the hearing they said yes he can go to a dyslexic school and that was the most stressful ... it was such a lot of trauma long procedure that was I think the most stressful".*

Susan also referred to being not understood and supported by the system which was meant to support her, with a tone of discontentment she explained:

Susan: *"when he does something really random and extreme and I phone CAMHS and say help and I get and I get a phone call back in two weeks that so if he is deciding to kill himself two weeks is not good ..... I lay awake I can't leave him, I can't go anywhere, you know, two weeks to phone me back and say well so and so is on sick for three months…"*

(v) Positive Outlook = Positive Adaptation: One of the superordinate themes that emerged during all the interviews was that of positive adaptation, it was evident that the parents made efforts to cope with the situation they are in by having a positive approach towards the disability of their child thereby mediating their levels of stress.

Transforming the self: Focussing on the positives was echoed various times during the interviews, it was clear that many parents have successfully adapted to the situation that they are in by adopting a positive approach towards life leading to positive growth, combating their stress and leading a fulfilling life.

Julia: "So there is stress probably on a daily basis and but I try to always look at the positives ... I often think O my God you know why have I getting to deal with all of this and then I stop and think that there are people out there that are far *worse off than I am… so it's actually sitting and reflecting on things and they are quite not as bad as you may have thought".*

Kate suggested that she has to make a conscious effort to look at the positive side of the entire situation but she makes the effort to do so to help her cope and function in a better manner, as she puts it:

Kate: "Yes, I certainly try to, I try to force myself to be positive if I feel gloomy, I try to think of better days and start to feel better, more energized.…I have coped with a lot, will deal with this too.".

Changing perceptions: Accepting the child's diagnosis and condition was suggested as a positive approach of dealing with the situation successfully and allowing the parents to plan the future realistically based on their child's abilities.

Kate: "... I am happy with the way things are, they could have been a lot different but not better, do you understand my point?... I love (daughter) to bits and wouldn't change her for the moon, I guess you need to accept that this is my daughter; she has a condition so we have to live with it… It can't be changed so accepting her the way she is and helping her enjoy life makes me enjoy life.

This extract suggests that despite the diagnosis of the child parents employ positive strategies for coping such as acceptance, which enables them to continue their journey with their child and the child's disability.

Discussion

The aim of this study was to identify the key challenges and stressors faced by parents of children with developmental disabilities and also the coping strategies used by them. The following section elaborates the findings of the present study in relation to how they support, refute or add to existing literature exploring the phenomenon of stress in parents of children with developmental disabilities. Findings will be integrated with psychological theory to gain a better understanding of the parents' experiences.

As noted in previous chapters, parenting a child with developmental disabilities is correlated with significant amounts of increased parental stress (Blacher & McIntyre, 2006; Chan & Sigafoos, 2000; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Eisenhower, Baker, & Blacher 2005; McHugh et al., 2008). Overall, the present analysis revealed that the participants viewed their role as a carer as extremely demanding and relentless, however, they also suggested that despite these overwhelming duties they loved their maternal role which was fulfilling emotionally. The overreaching themes from this research correlate with McCubbin and Patterson's Double ABCX Model of family stress (1983) which aims to explain the process of stress and coping at a familial level to provide how families change, adapt, approach and manage stressful situations. This model postulates that the mechanism of reacting to a stressful situation cannot be explained as a single event but as an evolving process in the family (Summers, Behr, & Turnbull, 1988). Subjected to the family's reactions, this could lead to adaptation resulting in an upward spiral of growth: bonadaptation; or a crisis or downward spiral of dysfunction: maladaptation (McCubbin & Patterson, 1983). In relevance to the interpretation of the interviews, the mothers' journeys include stressful experiences and challenges, which are similar to McCubbin and Patterson's aA-xX axis of family stressors and family crisis, inasmuch as strategies for coping and support, are corresponding to McCubbin's bB-cC axis of internal family resource and informal or formal social supports, and family perception and parental self-efficacy. (This model has been explained at length in Chapter Three).

The findings indicate that there is an initial period of disbelief amongst parents with the diagnosis of their child’s disability which consequently leads to a lot of stress. As Dunst et al. (1987) state that the integrity and well-being of the parents and the family as a whole are profoundly affected by the birth or raising of a child with a disability. The findings describe the different types of perceptions the parents hold for their caring role.

All the mothers in the study reported that they loved to fulfil their maternal role and enjoyed being the ‘mother’ most of the times, however, these (most) mothers also indicated at the same time that there role was far too relentless due to the immense effort they had to put into it as a result of their child’s condition. The mothers constantly see a shift from a ‘maternal role’ to a ‘carer role’; these identities and roles of a mother and carer are often altered and adjusted to provide optimal care for the child (Martin & Colbert, 1997). In the case of Carole, Lynn and Neala this role shift is very pronounced and as Carole suggested there is a shift between a love and hate relationship based on the role she plays at the time; however, the love for their child remains unscathed irrespective of the disability. As Green (2007), points out, ‘‘the burden of care’’ is a matter of socio-structural constraints (Objective Burden) rather than emotional distress (Subjective Burden) and despite the socio-structural constraints associated with caring for a child with complex needs, most mothers perceive valuable benefits in having a child with a disability (Green, 2007), as was reported by almost all mothers in the present study.

Fisher and Goodley (2007) have developed the idea that when parents report narratives of challenge, they tend to develop counter narratives so that they can enjoy their children in the present. Nearly all mothers and specially Lynn and Neala whilst speaking of the challenges and stressors they faced on a day to day basis while raising a child with a developmental disability repeatedly mentioned the love or joy they felt in having to raise this child. At the same time, the participants also mentioned that the realisation of their child's potential, brought sorrow, as Julia mentioned in her interview that she felt sad because of other families and felt envious of what their children were achieving and regretted that her child would not be able to accomplish those goals at that age. Smith et al. (2006), acknowledge this concern and write that the realisation of a child's changed potential is a source of sorrow for parents with disabled children.

A paradox of emotions was clearly highlighted in the mothers' accounts, as they suggested how they loved to care for their child but how this 'care' could turn into a 'burden' for them due to its incessant unending nature. This paradox of emotions can also be viewed as a fragmented experience of parenting because of the shifting role between the 'carer' and the 'mother' (parent). A milder form of this process may be explanatory for any of the participants, but is particularly congruent with Neala's description as she states, that she feels drained, exhausted and tired with her role but still finds it rewarding at the same time. Many mothers in the present study indicated that they were governed by an extreme sense of responsibility and were bound by a sense of unending duty towards the child. This may often lead the parents to have an internal struggle between their own emotional feelings and their relentless sense of duty resulting in the paradox of a love and hate relationship with their caring role.

All mothers participating in the study reported that they suffered from physical exhaustion and fatigue due to the nature of their caring role. It is also to be noted that many respondents also indicated that there have not been many changes in the amount or type of care they provide to their children as they are growing up. As Martin & Colbert, (1987) state parenting a child with developmental disabilities not only affects the intensity of caregiving, but also results in extending the period of parental caregiving, as the development of autonomy for children with disabilities is often compromised and/or delayed.

The mothers in the present study indicated that their children's' caring demands have been more or less constant. They explained that these demands may have changed over time but not necessarily reduced. Unlike typically developing children, children with developmental disabilities may be dependent on their care givers for a longer period of time depending upon their condition. Mackey and Goddard (2006), for example, report that fatigue and tiredness of parents are a result of being ever vigilant and alert, and partly due to lack of respite from their caring role irrespective of the child's age. This key finding of their study resonates with the accounts of the mothers in the present study.

All participants in the present study indicated that their caring role was constant with no opportunities for a break or respite. The mothers stated that the care giving demands placed on them were rather constant and in most cases they did not have an option to sit back however much they wanted to. Consequently, exhaustion and burnout are common among many parents caring for a child with developmental disabilities (Martin & Colbert, 1997).

Previous research also indicates that the amount of stress reported by parents is related consistently to the diagnosis of the child (Keller & Honig, 2004; Cummings, 1976; Palfrey et al.; 1989; Hastings, 2002, Smith et al., 2006), for example, the complex the diagnosis, the higher the stress reported by parents. However, there are other studies which indicate that it may not be the diagnosis, but rather the child characteristics associated with the diagnosis (e.g. behaviour problems or care needs) that are the key predictors of stress in parents. The children's characteristics are also an important factor to consider, with consistent associations and links between higher levels of the various dimensions of parental stress (Floyd & Gallagher, 2007; Baker, McIntyre & Blacher, 2003). Challenging child behaviours for example, hitting, biting, banging heads against hard surfaces etc. can be a major source of stress and require constant supervision to ensure the safety of the child and other family members (Kobe et al., 1991; Hodapp & Zigler, 1985). All mothers in the present study reported that child variables such as the behaviour of the child and care needs due to their diagnosis were a major source of worry and burden for them, indicating that it is both the diagnosis as well as the child characteristics which act as persistent stressors for them.

Child maladaptive behaviour has been associated with increased burden and stress (Heller, Hsieh, & Rowitz, 1997; Saloviita, Italinna, & Leinonen, 2003; Johnston et al., 2003; Raina et al., 2005).Simmerman, Blacher, & Baker, 2001) and poorer parenting efficacy (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). In Maria's case her son's behaviour (hitting her) has been a constant source of worry and this has made it harder for her to take care of him as he is growing up.

Literature suggests that due to the condition of the child, the parent may also be highly responsible for the child's personal care needs (Neely-Barnes& Marcenko, 2004; Plant & Sanders, 2007); and medical needs (Neely-Barnes & Marcenko, 2004) causing high levels of stress and burden; which was reflected in most cases in the present study. Unusual care giving demands are also positively correlated with higher levels of exhaustion and parent problems, Beckmen-Bell, (1981) found that unusual caring demands accounted for 66% of the variance in the number of parent problems reported in their study. Findings from a study by McKinney and Peterson (1985) indicated that children with moderate to severe impairments placed more demands on the mother due to significant impairments to their growth and development; physical exhaustion in the parents is therefore very closely linked to the level of dependence the child has on the parent to meet their day to day needs. This links with the findings that all the participants in the present study were solely and highly responsible for meeting their child's personal needs as they were the only ones' who knew the child's needs in detail and also were well equipped with meeting these.

Consistent with previous qualitative studies such as Zetlin and Turner's (1985) study, where parents with young disabled children, expressed fear about their child's sexuality, social interactions, friendships, and ultimate level of independence; participants in the present study had similar concerns. They reported that as their child is growing physically and maturing their worries about their vulnerabilities are increasing due to the child's lack of capacity to make informed decisions. An increased vulnerability to abuse and fears of this kind are a repetitive theme from parents of adolescents (Hallum, 1995) and was a concern amongst parents in this study too.

For many parents, responsibilities and the burden of care for their disabled child will increase instead of decrease as the child grows (Gallagher, Beckman &

Cross, 1983; Wilder, Wasow, & Hatfield, 1981; Bristol, & Schopler, 1983). In the case of children with developmental disabilities, parents of the maturing adolescent must also cope with the increasing physical size of their child and as the child becomes taller and heavier, parents report more stress related to the physical burden of care.

Lifting, transferring, bathing, and dressing the older physically dependent child can become physically very difficult for parents, especially mothers. Most mothers in the present study reported that they find it hard to cope with the increasing physical burden of care as their child is maturing. For example, Judith implied at various points during her interview that she cannot control many of her son's behaviours as he's growing physically. Similarly, Lynn who has a two year old child said that it has started to worry her from this early stage that how will she cope with the increasing physical demands of her active child as he grows, indicating how much of a concern the growing physical strength is for her as she finds it hard to cope with her very active child.

Participants in the present study reported that they feel 'strengthened' by what they do for their children. They reported gaining new perspectives following overwhelming changes in personal beliefs and values; and becoming stronger in the face of adversity. Despite adversity, most of the parents in the present study reported inner strengths and were incredibly resilient. Finding strengths that parents never knew they had is an indication of the parents trying hard to overcome the barriers in caring for their disabled child. A possible lack of strength or weakness in them may cause a disruption in their and their child's life so they tend to develop strengths over time which may assist them to overcome problems.

Almost all the participants in the present study indicated that they ‘recognised strengths’ they never knew they had whilst caring for their child. However, like Jane, most of them insisted that they realised these strengths not because they ‘wanted to’ but because they ‘had to’. In order for them to remain strong the mothers acquired strengths which were considered as vital and necessary for the up-liftment of their child. Scorgie and Sobsey (2000), report that one of the acquired traits rated highest by the parents of disabled children was the ability to speak out on behalf of their children. For some parents it was a long and difficult learning process that stemmed largely from their desire to protect and support their child with disabilities and was often done to fight against the discrimination and difficulties associated with accessing equal services.

Parents have reported the exhilaration of knowing that through advocacy they have “made a difference” in someone else’s life (Scorgie & Sobsey, 2000). Participants in the present study also indicated that they have in many cases have acquired the strength and ability to “voice” the needs of their child so they can be met appropriately. As with

Judith’s interview her descriptions reflected that she found the strength and courage to represent her son’s needs so they may be dealt with more effectively giving him what he requires and at the same time giving Judith the peace of mind thinking that she has accomplished what was required for her son’s well-being. This revelation of strength in the participants can be understood in terms of their feeling of empowerment and feeling more in control of the situation, giving them more confidence to deal with the stressors in their lives.

Stress levels appear to be unremitting and persistent over extensive periods of time in parents of children with disabilities (Glidden & Schoolcraft, 2003). Parents of children with typical development have the potential relief of sharing household responsibilities with other members of the family, whereas, in the case of caring for a child with disabilities the parents may be the sole providers of care of extended periods of time, which is both physically and emotionally draining (Turnbull et al., 1986; Wilker, 1981). All the participants in the present study reported time and again that they felt diminished as they did not have the chance to choose; they had to perform a duty ceaselessly, not because they wanted to but because they had to; because if they would not no one else would.

This lack of choice was most pronounced in Julia's account where she mentioned if she had a choice she would not perform the caring role she had to because of the stress it caused to her, but having no other option she had to continue playing her role. Lynn also portrayed a similar picture in her interview. The accounts of these mothers suggested, that they found it hard to balance the demands of the child's and the family's normal life against the demands of the disability, as suggested by Featherstone (1980) because of the feeling of obligation towards the duty of care and responsibility towards their child with the disability.

The second area explored in relation to the research question aimed at identifying the range of coping strategies used by parents of children with developmental disabilities. Although parents of developmentally delayed children experience periodic sadness and stress, many are able to cope successfully (Crnic, Friedrich, & Greenberg, 1983). The findings of this study revealed that parents reported both active and passive strategies to alleviate stress, this is consistent with previous research on stress (Folkman et al., 2000; Minnes, 1988). Parents identified that it was important to use effective coping techniques to control their levels of stress and manage their emotions, they identified the importance of varying coping techniques based on their effectiveness in a particular situation. This is consistent Folkman & Moskowitz's (2004) suggestion that the use of effective coping strategies can regulate stress and resultant emotions.

Participants in the present research showed an inclination towards personal coping techniques which refer to the efforts made by an individual acting as her or his own resource, rather than seeking support, assistance, or validation from the social environment due to the uniqueness of the situation they are in (Schilling, Gilchrist & Schinke, 1984).

Personal resources influence a person's ability to cope effectively in stressful situations. When people have a sufficient amount of personal resources available to them, they are less likely to view the situation as stressful (McCubbin et al., 1980). In the case of having a child with a developmental disability parents are aware of their unique responsibility. They understand in most cases that this in one sense is their own 'private burden' (Featherstone, 1980) and therefore devise their own personal coping strategies. These strategies may work alongside the personal resources they have available at the time for example, basic personal resources i.e. financial, health, educational and psychological can all be brought to use to aid the stressful situation (Yau & Li Tsang, 1999).

Overall, the participants in the present study suggested that different ways of coping worked for them. The parents in the current study identified both practical and emotional strategies for coping.

Some of the participants in the study indicated that they deliberately try and avoid certain situations which they know can cause them stress, hence, they are able to cope with a potential stressor by avoiding it. For example, Jane, stated that she keeps herself very busy all the time and keeping busy perhaps does not give her much time to dwell over the problem or the stress it causes. This form of coping can be classified as avoidance coping embedded in an emotion focused style of coping as the mother is making a conscious attempt to avoid the stressor and at the same time regulate her emotions and retain or gain a sense of calmness.

The analysis of the present study also indicated that various participants indulged in 'distraction' as a coping strategy, which involves actively focusing attention away from one's physiological, cognitive or emotional response to a stressful situation (Phelps, 2005). Maria, Susan and Carole all gave examples of things they would do to moderate their levels of stress which can be classified as types of distraction techniques. These findings also link to literature emphasising the importance of distraction techniques as permitting individuals to control their intrusive worries by engaging in various tasks or activities and leading to positive outcomes involving a temporary escape from the negative emotions associated with a stressful situation (Compas et al., 1997).

Having time for oneself where one can relieve stress is also an effective coping mechanism (Hallum, 1995) and was used as an effective coping mechanism this was reportedly used by various mothers in the present study. A study conducted by Taanila, Syrjälä, Kokkonen and Järvelin (2001), concluded that it is important that the parents have time for themselves and their hobbies as this can help them to cope with the stressful situation caused by the child. This form of coping where individuals distract themselves from intrusive thoughts can be viewed as an effective short-term emotion focused coping technique and was used as a coping mechanism by Carole, Susan, Maria, Jane, Neala in the present study.

Studies focusing on strengths in families with a disabled child have found that using effective information and help seeking strategies (Darling, 1988) are a successful way of dealing with stress. This form of coping can be classified as problem-focused coping as an individual in this case tries to resolve or ease the problem or stressor to a certain degree by actively trying to seek ways which can mediate the stressful affect.

This study revealed that various participants in the present study indicated that they made use of problem focused coping to deal with their stress. Problem focused coping includes efforts directed at acquiring resources (e.g., skills, tools and knowledge) to help deal with the underlying problem, and instrumental, situation-specific, task oriented actions (Lazarus & Folkman, 1984).

In the present study, mothers stated that in order to gain updated information about their child's condition they tend to join various support groups or online forums. Doing this gives them a better understanding of their child's condition and more practical guidance and support, which links with findings that, that parents involved in a parent-to-parent or other support groups report an increase in their positive perceptions of their child with a disability (Singer et al., 1999). Research also indicates that individuals who have access to social support are protected against the emotional and physical effects of stress (Pilisuk & Hillier-Parks, 1983), for example, sharing of information that often occurs in support groups may also lead to a greater sense of empowerment in the parents.

The findings of this study indicate that an important problem focused strategy that parents reported to be very useful was the access to information. It was revealed that the parents would draw on their own personal resources, and ensure they were well-informed about their child's diagnosis, and would actively seek information relevant to their child's condition as this would give them a better understanding of their child's situation resulting in a feeling of less stress and more in control of the situation. The link between adequate information about the child's disability and implications of parental coping has been well documented in disability literature. Taanila, Syrjälä, Kokkonen and Järvelin, (2001), found out that the parents who were of the opinion that they had been informed well about their child's diagnosis and treatment, and had themselves sought information actively to cope in the stressful situation were able to cope much better than the others. The parents in their study felt that a realistic outlook of the child's disability and acceptance of the situation had helped them to cope, as, Burr & Klein et al., (1994) reported in their study that for parents coping with the added stress of raising a child with disabilities accepting the situation was a very helpful coping strategy. Abbott and Meredith (1986) found that well-functioning families focus on their child's strengths or abilities, rather than their limitations and that the successful adaptation of having a child with a disability was accomplished when the parents defined their situation in a positive way. Adequate information about the child's disability is important and helps the parents to cope, whereas an ambiguity of diagnosis and expectations gives rise to stress and isolation in the family (Burr & Klein 1994; Gibson 1995; Taanila et al. 1996; 1998).

Further forms of adaptive coping noted in previous research (e.g. Grant & Ramcharan 2001; Hastings et al. 2002; Todd et al. 1993) were also illustrated in this study, for example, caregivers' positive perceptions of their child, impact on the family, engagement in hobbies or pastimes and favourable perceptions of their own life situation.

However, at the same time the mothers discussed the feeling of social isolation they felt due to the high care involved in raising their child. The intense support for caring for a child with a disability brings with it personal costs which include feelings of being isolated from others as well as reduced social contact with friends in the community (Lane et al., 2000). A recurrent theme which emerged during the present study was an experience of isolation which the participants reported. Studies indicate that families with children with developmental disabilities may experience isolation in different ways, such as due to lack of social interaction due to financial and time constraints and due to fear of people being judgemental or insensitive about their child or the situation they are in (Contact a family, 2011).

There were clear themes of isolation in Maria and Julia's accounts, in Susan's description she seemed overwhelmed by her feeling of not being able to socialise to the extent that she reported that she avoids going out with friends as she has lost her confidence of being with people over the years she has been caring for her child. Many participants reported a sense of isolation because of the feeling that no one else shared their experience highlighting their unique situation (Barakat & Linney, 1992; Park & Turnbull, 2002).

Parents in the present study identified a wide range of services that they accessed regularly in relation to their children; the broad service areas covered in this research were: health, education and social-care. Most of the parents indicated that they have had to 'fight the system' to have their child's needs met at some point or the other, they felt that they had ‘struggled’ to gain access to services especially during transitions in school. Advocacy is crucial in the process of obtaining necessary services (Karp & Bradley, 1991). Securing appropriate services can prove to be a stressful responsibility for parents (Martin & Colbert, 1997). Previous studies are also indicative of similar findings; for example, parents describe it a battle to understand the roles of different agencies and individuals aimed at helping them (Beresford, 1995, Contact a family, 2010; Minnes & Nachsen, 1997; Todis & Singer, 1991). Struggling to get their needs met via the services often led a feeling of being lonely in the participants.

Kearney and Griffin, (2001) also report similar findings where their study participants reported that they felt sorrowful by experiences of the impact of the health system, which left many parents with a sense that they were on their own, leading them to feel vulnerable and powerless.

There is a strong relationship between parental stress and social support provision (Baker, McIntyre & Blacher, 2003; Floyd & Gallagher, 2007). Studies of parents of children with developmental disabilities have documented the existence of a concurrent association between social support and parental stress during both early childhood and school age (Beckman, 1991; Duis & Summers, 2007; Seltzer & Krauss 2003). The present study also reveals that most of the mothers struggled with this aspect and therefore felt much stressed due the inefficacy in most provisions.

Despite the adversities, most mothers in this study reported the positive transformation they have gone through in raising their child with a disability and how they have expressed the need for a strong belief in the child and in the child’s future, in maintaining an optimistic outlook along with a realistic view and acceptance of the situation.

Several researchers have demonstrated that raising a child with a developmental disability may lead to positive experiences and enrich the lives of the caregivers (Konrad, 2006; Mullins, 1987; Resch et al., 2010). Despite considering constant caring for their growing child as a challenge, the mothers' maintained a positive view of their relationship with the child. Lazarus, Kanner and Folkman (1980) argued that under stressful conditions, when negative emotions are predominant, positive emotions may lend a psychological break or respite, replenish resources and rejuvenate continued coping efforts to combat the effects of stress.

Crnic et al. (1983) and Dunst et al. (1987) include parental self-concept as an important part of parental perceptions. The way in which people define their problems is primarily determined by their perceptions. Positive perceptions play an important role in the coping process and help individuals to cope better with traumatic and stressful events (Hastings & Brown, 2002; Taylor, 1983). It is important to note that positive feelings towards their caring role have been echoed many times during the present study. Hobfoll (1989) commented that people are often keyed to respond to the adverse sequelae of loss by turning their attention to their resources and looking for positive aspects of their lives. There is mounting evidence in the literature on loss and trauma that finding benefits can have a positive impact on both emotional and physical health e.g.(Affleck, Tennen, & Croog, 1987; Bonanno, Wortman, & Nesse, 2002; Saloviita, Itaelinna & Leinonen, 2003). One of the participants in the present study (Julia) projected that thinking about the positive side of things and about people who are less fortunate than her makes her feel better instantly.

Positive appraisal of a stressful situation leads an individual to employ cognitive strategies for reframing a situation in order to see it in a more positive light (Folkman & Mosokowitz, 2000). Positive reappraisal enables the individual to appraise a difficult situation more positively. Many mothers in the present study commented that they are able to perceive their child's disability in a better manner now, which indicates that they have or are gradually adapting to the situation with a positive approach.

Limitations

Though this study contributes to past research conducted with families who have a child with a disability, there are certain limitations to it. While the limitations do not invalidate the study results, they do serve as reminders to interpret the findings with caution. The exploratory nature of this study prevents any firm conclusions or generalizations being drawn. However, provided the lack of research investigating the psychological responses in terms of coping interventions and their effect on parental wellbeing, the present study provided valuable data which informed the development of the next study (Chapter Four).

All participants in this study were mothers which may be a potential limitation in terms of the generalization of this study. However, studies in disability literature confirm that this has always been the case as mothers are most often the main care providers of the child and may leave work to care full time for the child because of because of time constraints, providing specialist care and partly because of the cost of substitute care for the cared for child (e.g. Angrist & Evans, 1998; Hauser- Cram et al., 2001; Kagan, Lewis, Heaton, & Cranshaw, 1999; Meyers, Lukemeyer, & Smeeding, 1998; Pelchat et al., 2003; Quinn, 1999)

Another drawback of this study is the lack of face-to-face interviews for data collection. A majority of parents participating in this study, opted for telephonic interviews. Opdenakker (2006); and Sturges & Hanrahan (2004) point out that telephone interviews are a versatile way of gathering data, however, Fontana & Frey (2005); and Garbett & McCormack (2001) highlight the importance of nonverbal interview data such as the emotional content which in turn contributes to the depth and overall quality of the data collection which is missing in a telephone interview. Aquilino (1994), and Carr & Worth (2001) point out some of the disadvantages of telephone interviews, such as a lack of visual cues and the potential for distraction by participants in their own environment. Other disadvantages include the fact that for the most part telephone interviews are in general much shorter than face-to-face interviews. However, as most parents in the study experienced extreme care giving demands and had tight schedules of duty they had very little time to accommodate face-to-face interviews. Further studies should take the limitations of this study into consideration.

Conclusions

In summary, parents in this study reported about the various challenges and stressors they face in raising a child with a disability and how they employ suitable strategies for coping with these stresses to gain a more positive parenting experience. It was also indicated that the stresses or adversities may change time to time and therefore the parents need to continuously reframe their coping strategies to mediate their levels of stress.

The results of this exploratory study suggest that key developmental stages do not necessarily provoke high levels of distress in parents. However, parents still have concerns about the implications and practicalities about the changes that transitions involve for their child. Parents revealed that they do go through daily hassles and stress whilst caring for their child but most of them also suggested that they have positively appraised their child’s disability and have adapted to it making necessary adaptations in their lives. The parents indicated that they struggle within their role of a parent and constant carer due to the high demanding care role which is the cause of much day to day stress they encounter. Additionally, the results of this study also revealed important information about the preferential coping strategies which parents use and this would be used as a guide develop the coping intervention in the following study. The mothers in the present study also seem to have embraced the paradox of love and hate in relation to their child’s disability, which led them to have a perception of control and a more positive conscious experience of their life as parent-carers. This positivity and optimism bolster subjective well-being within the mothers and helps them to manage and control aspects of their lives which may be stressful if not managed appropriately. To conclude:

“In embracing the paradox of their child's disability these mothers attempt to render a disruption of life into a beautiful pearl and are themselves transformed through this alchemy to individuals with deep appreciation for the value of all life, despite the daily struggles.” (Larson, 1998, pp. 873).

Overall, the results of this study indicated a perception of a high levels of stress amongst parents of children with developmental disabilities indicating that it is important to aim for interventions which may assist these parents to reduce their levels of stress and promote well-being amongst them. The following chapter reports the second study of this thesis which assesses the acceptability of the intervention designed to minimise stress and promote well-being in parents of children with developmental disabilities.

CHAPTER 6

Study Two: A pilot study of the Self-Help Coping Intervention

The review of literature (Chapters Two and Three) and the first qualitative study (Chapter Five) of this thesis highlight the need and justification for the development of a coping intervention for parents caring for children with developmental disabilities. The focus and development of this complex intervention will be discussed in this chapter, which also reports the second study of the thesis which is a pilot study corresponding to the Medical Research Council Phase I trial for the development and evaluation of complex interventions (Craig et al., 2008). The aim of this qualitative study is to examine the acceptability and feasibility of the self-help coping leaflet (a complex intervention) designed to promote the effective use of coping strategies and enhance well-being in parents of children with developmental disabilities. This study also aims to explore the preferences, appeal and ease of usage of specific coping techniques mentioned on the leaflet. The MRC guidance (2008), advises that intervention development should include three stages that of i) identifying an existing evidence base (Chapters Two, and Five); ii) identifying or developing appropriate theory (Chapter 3); and iii) modelling the processes and outcomes. Henceforth, it is necessary to explore its acceptability so that any weaknesses may be identified, and refinements undertaken. The following section reports the development and focus of the coping intervention; this is followed by reporting the second study of this thesis, which elaborates the process of assessing the acceptability and feasibility of the self-help coping intervention by parents of children with developmental disabilities.

Development of a theory-based coping intervention

According to the Medical Research Council (2000) to be able to design and develop effective interventions; researchers need to follow a rational, systematic approach to identify and select appropriate components to bring about the change desired by the implementation of their intervention (MRC, 2000, Michie, van Stralen and West, 2011). In accordance with the MRC guidelines, the self-help coping leaflet intervention in this thesis was adapted and developed to gain a better understanding of the likely process and effects of coping in parents caring for children with developmental disabilities (Craig et al, 2008; MRC, 2000, 2008). Based on its components, function and outcomes this intervention can be classified as a complex intervention. These type of interventions are made up of various interacting components, have several dimensions, and includes a number of interactions between its elements; a number of potential outcomes; and a permissible degree of flexibility (MRC, 2008). The intervention developed in this study is a self- help coping leaflet which was adapted for parents of children with developmental disabilities with the aim that it may be (1) theoretically derived, (2) simple enough for parents to use by themselves, (3) could be used by parents whenever and wherever they felt the need, (4) cost-effective enough to be made freely available, and (5) was generic enough to be used by parents caring for children with different diagnoses or severity of symptoms. Consideration of how a coping leaflet fulfilling the above criteria could be delivered led to the development of a simple, A4 sized leaflet containing the instructions about the various coping techniques that the parent could engage in (Appendix B.1). It is assumed that the coping techniques included in the leaflet are likely to be helpful in promoting a sense of well-being and reducing stress amongst users. The conceptual simplicity and the relative ease of the coping techniques in the current intervention can be easily taught through written instruction making the leaflet a viable mode for intervention delivery. In the field of childhood disability, such an intervention is novel and may prove highly effective where there are limited opportunities for parents to engage in practitioner based interventions for pragmatic and economic reasons. For practical reasons such as ease of use and the extent of written content, the coping techniques are mentioned briefly but with clear instructions to the reader. The leaflet clearly provides the reader with the instructions, options and methods of using the various techniques, and also illustrates the coping techniques with certain picture clues for the users. The leaflet also has an online version which with present day technological advances is a promising alternative to a hard copy based leaflet and once downloaded can be accessed at anytime, anywhere. In addition, the leaflet whether as a paper based version or online does not require individuals to travel to a physical location to receive instruction, is less expensive to deliver, and more importantly maintains privacy (Amstadter et al., 2009) for those sensitive to their personal circumstance of parenting a child with a developmental disability. Importantly, the leaflet can be used by the parents according to their need thereby diminishing any professional dominance which may be stressful for some individuals (Winton et al., 1999).

Focus of the Intervention: With the aim to help parents of children with developmental disabilities in moderating their levels of day to day parental stress and enhance their wellbeing the self-help coping intervention (Appendix B.1) was developed as a part of this study. This intervention has been adapted from a previously used coping intervention which was aimed, created for and tested on a population of patients undergoing cancer genetic risk assessment (Bennet, Phelps, Brain, Hood & Gray, 2007; Phelps, Bennett, Hood, Brain & Murray, 2012). The original coping leaflet (Phelps, 2005) was designed to help patients deal with their distress while undergoing cancer genetic risk assessment. This leaflet promoted the use of various cognitive and behavioural distraction techniques allowing set periods for emotional processing and future planning at the same time; the present version of this leaflet adapted for parents of children with disabilities also aims to help parents deal with their stress. Similar studies assessing patient distress whilst waiting for the outcomes of medical procedures or tests reveal that emotion focussed strategies are negatively associated with stress partly due to the fact that the outcome of the tests cannot be changed (Lowe et al., 2003; Phelps et al., 2012). The use of similar interventions based on positive reappraisal have also been promising, a study conducted by Lancastle and Boivin (2008), aimed to establish whether a novel brief coping intervention (positive reappraisal coping intervention, PRCI) card that encouraged women waiting for an IVF pregnancy test to redefine the waiting period more positively would be acceptable and practical for the users. The women (n= 55) were randomly assigned to groups on the day of embryo transfer. They read either 10 statements in a PRCI (n = 28) or 10 statements in a positive self-affirmative (positive mood) intervention (PMI; n =27) twice daily for 14 days between embryo transfer (Time One) and the pregnancy test (Time Two). At Time Two, the card was evaluated for its practicality, acceptability, perceived benefits and endorsements. The results revealed that in comparison to the PMI, the PRCI was rated as an acceptable, feasible intervention, helping women to feel more positive and better helping to sustain efforts to cope. The current intervention in this thesis also promotes the use of benefit finding which stems from the principles of positive reappraisal encouraging the use of cognitive strategies for reframing a situation to see it in a positive light (Folkman & Moskowitz, 2000).

The self-help coping leaflet includes an array of coping responses. The provision of a meta strategy to provide an optimum coping response for a particular stressful event is important because research suggests that the effectiveness of individual coping strategies can vary at different times depending upon the context of the situation (Hanson, Buckelew, Hewett, & O'Neal, 1993; Reidy & Caplan, 1994). For example, the leaflet includes information on various coping techniques such as 'worry postponement' which may help in allowing the individual to control the time spent on worrying about the future. Based on Brosschot and Van Der Doefs' (2006) suggestion that it may be an easier option to help individuals to restrict the amount of time they spend on worrying rather than attempting to decrease the frequency with which worries appear in awareness. The leaflet also includes information on emotional expression through 'expressive writings' and 'benefit finding' as research suggests that finding benefits and expressing emotions through writings in relation to stressful experiences have been associated in correlational research with positive adjustment (Stanton et al., 2002).

Numerous studies report that engaging in a distraction task decreases depressed mood and reduces distress (Bennett et al., 2007; Butler & Nolen-Hoeksema, 1994; Phelps et al., 2006; Phelps et al., 2013). The leaflet encourages parents to engage in benign distracting activities as soon as they experience intrusive thoughts to manage periods of negative mood. Considering concerns that distraction may inhibit individuals from dealing with important issues or adapting to the stressful situation (Carels et al., 2004), the leaflet also suggests the users to allocate to themselves a set period of time during the day for emotional processing to think about the concerns and future of their child. The proposed intervention in this study includes more scope and variety (e.g. benefit finding, distraction etc.) which may assist parents in coping with their worries.

The review of literature (Chapter Two, page 47-59) in this thesis also suggested that a large proportion of the interventions reviewed were based on mainly problem focussed coping strategies (e.g. Behavioural Parent Training, Parent Empowerment Training). In particular, it has been assumed that problem focused coping strategies are more successful than emotion focused coping strategies and that men are more likely than women to engage in problem focused coping strategies and women more likely than men to engage in emotion focused coping strategies (Thoits, 1991, 1995). However, coping research has indicated that coping may be more complex than these assumptions suggest (Lazarus, 1996; Thoits, 1995). There has been an inconsistent relationship between coping strategies and outcomes in many studies, suggesting that one form of coping may be more or less beneficial than the other depending upon the individuals using these strategies and their unique circumstances (Gray, 2003). Evidence also points out that the nature of a stressful event may have an impact on the success of a coping strategy. For example, the use of an emotion focused coping strategy may be more useful than a problem focused coping strategy where the problem is not amenable to a solution (Borden & Berlin, 1990; Lazarus, 1993, 1996). The current self-help coping leaflet constitutes of an array of activities practicing which may help parents to reduce their level of stress, such as taking time out for themselves (emotion focused), expressive writing (emotion focussed), benefit finding (reappraisal, emotion focussed) and distraction from worries (emotion focussed). The promotion of the use of emotion focused coping is based on the idea that a developmental disability is a lifelong condition and hence not amenable to change therefore the use of emotion focused coping strategies can help parents to deal better with their stress. Over time, parents gain a level of expertise managing their child's condition and therefore need to continuously aim to adapt their coping style according to their situational factors which in some cases maybe dealing with the emotional aspect of their caring role in order to improve their own well-being.

Most of the interventions discussed at length in chapter two, (section: Psychological Interventions for parents caring for children with developmental disabilities page 47-59) constitute of parenting education, use of instruction and guidance from professionals and professional dominance due to the teaching and learning of new skills in the parents (e.g. Baker et al., 2002; Baxter, Cummins & Yiolitis, 2000; Gammon & Rose, 1991; Singer, , Ethridge, & Aldana, 2007; Sofronoff, Leslie,& Brown, 2004). Winton et al., (1999) criticize these kind of interventions due to a number of reasons such as, pressing demands on the parent's time, feeling of a lack of self-confidence and self-efficacy due to professional dominance and lack of understanding and appreciation towards individual circumstances and cultural differences. The self-help coping intervention in this study has been adapted for parents whilst keeping in mind such criticism and hence gives the parent a chance to choose any coping mechanism which works for them and practice it at their own free will after judging its efficacy for their situation without the involvement of the researcher or any other professional. The leaflet which is relatively novel in terms of its delivery and application also gives the parent an opportunity to practice the techniques mentioned in it based on their time and convenience therefore allowing them to use their free will and time to practice whenever they can. The review of intervention studies in this cohort reveals that there are no coping leaflets used as interventions for these parents at the present moment. This intervention therefore is innovative and aims to alter the parents' well-being rather than offering support to the entire family. Whilst a family approach can be effective in addressing the issue of stress and coping, it was not considered to deliver the present intervention to the entire family unit due to various practical and pragmatic reasons. This is an exploratory study aimed at finding out the effectiveness of the self-help coping leaflet for the parent, it was hoped that the results from the present study may initiate the development and use of the leaflet for the entire family in the future. It was also not considered to develop this an intervention for the entire family because of its' individualised approach and pragmatic reasons such as delivery of the intervention to different members of the family. To have a familial approach, the leaflet would have to be adapted for various members in the family unit, for example for siblings who may be of a very varied age range, or grandparents who may appraise the stress very differently and use very different coping mechanisms (Katz, & Kessel, 2002; Mitchell, 2007) in comparison to the younger family members etc. Other pragmatic reasons such as difficulty in potential recruitment, expenses and time constraints were also factors which contributed to the leaflet being offered to the parents or primary care givers only. It was also considered that if the intervention is successful in promoting coping effectiveness and minimising stress in this study, the parent using it may feel more in control of the entire situation and this sense of control may positively affect not just the parent but have a ripple effect on the entire family unit (Hassall, Rose & McDonald, 2005). The nature and purpose of this leaflet was such that it was designed to be used by parents anytime based on their convenience and within the vicinity of their home or personal space. The techniques promoted on the leaflet also do not require any sort of contact or communication with another person so the parents can maintain a sense of self-reliance in terms of the coping strategies they can choose and implement based on their personal circumstances.

The results of first study of this thesis indicated that most parents felt isolated due to their caring responsibilities; however, ideas for sourcing social support were not promoted in order to maintain the self-reliant nature of this leaflet, which only promoted techniques that could benefit the parent without any or with minimal reliance on another individual. The results of the first study also highlighted that some parents do not prefer to socialise much because of a feeling of lack of understanding from others towards their personal circumstances and thus it was considered that they may not want to socialise beyond their own comfortable space considering their unique situation. This feeling of a lack of understanding is congruent with previous literature highlighting the significant challenges faced by these parents were consistently related to a lack of knowledge and understanding by others (Brett, 2002; Gray, 2002; Jones, & Passey, 2004; Woodgate, Ateah, & Secco, 2008). However, the benefits of socialising (e.g. Boyd, 2002; Carter et al., 2004; Siklos, & Kerns, 2006; Weiss, 2002) outweigh these concerns in most cases and in hindsight this may have been a useful coping mechanism for many parents as it could be controlled or manipulated by the parent in accordance with their free-will.

Pre- testing: In order to ensure that the content on the leaflet was readable and understandable, the draft version of the leaflet was pre-tested for readability for elements of complexity, familiarity, legibility and typography. This was assessed using the Flesch-Kincaid readability test, the results indicated that the text was ‘fairly easy to read’ with the leaflet content obtaining a score of Flesch-Kincaid Grade level 7.6 and Flesch reading ease 71.6. The leaflet was also deemed as easy to read and understand by the study supervisor and another Psychology research student and the content of the leaflet (in terms of readability) was thus considered appropriate to administer for parents.

The following section reports the second study of this thesis which aimed to assess the acceptability and feasibility of this self-help coping leaflet (Appendix B.1).

Study Aims

The aim of this study was to pilot the self-help coping leaflet intervention designed to reduce stress and improve well-being amongst parents of children with developmental disabilities and also to assess its acceptability within this population group. This stage of the research corresponded to the MRC Phase I research for complex interventions and was exploratory in nature. In line with the guidelines issued by the MRC (2000) for the development of complex interventions, this phase of the study aimed to provide evidence that could be used identify weaknesses leading to refinements or to indicate that a full-scale evaluation may be unwarranted due to disapproval. It was intended that the findings from this study would inform the final study in two important ways. Firstly, the feedback gained on the self-help coping leaflet in this phase of the study would be an important step in developing the final version of the intervention. Secondly, the knowledge gained from this interview study would aid in the selection and design of questionnaires for the next study by enabling the identification of key issues such as the impact of the intervention on stress, coping and psychological well-being of parents who participated in this pilot study. The specific objectives of the study were to:

Assess the acceptability and relevance of the self-help coping intervention.

To explore the preferences, choices and ease of usage of specific coping strategies.

Method

Design

The present study was a pilot of the self-help coping intervention, the results of which assisted in improving the intervention and evaluating the procedure of the final exploratory study. As fundamental for the design of a pilot study, there was a set of well-defined aims to ensure methodological rigour; and a descriptive form of analysis (Lancaster, Dodd & Williamson, 2004) to meet the objectives of this study.

Participants: *Target Population*

The target participants for the present study were parents (mother or father) of children diagnosed with a developmental disability aged up to 16 years living in Swansea (UK).

Inclusion and exclusion criteria

Participants were deemed suitable for participation if they were:

A parent with a child diagnosed with a developmental disability.

If this child was aged 0-16 years.

A parent who was able to give informed consent.

Participants were deemed unsuitable if they were:

A parent who could not communicate in the mode of English as the mode of delivery of the intervention was English.

Recruitment Procedure

Given the small scale nature of this study, a decision was made to try and recruit locally through existing contacts and organisations within the local regions. Following ethical approval, the study was advertised through the social network page of Cerebra, (a charity for children with developmental disabilities); various parent support groups within the Swansea area were also contacted via email and telephone and one to one meetings (SCVS Parents group, Handsupfordowns, Contactafamily, Autismlinks), schools with a special education needs support were also contacted via email (Cadle Primary, Danygraig Primary, Crug Glas). Out of all the organizations and groups contacted, only one parent support group got back to the researcher with an expression of interest. The researcher then organised to meet all the members of this group at a mutually agreed venue, date and time to explain to them about her research and the intervention. The group was briefed about the research and its aim and the importance of conducting a pilot study. They were asked to read the simple study information sheet (Appendix B.2); and, before deciding whether to take part in the study or not were given the opportunity to ask questions about it. Only those providing written consent were included in the study.

Final sample

After meeting the researcher and reading the information sheet, seven out of nine mothers of the parent support group (Handsupfordowns) agreed to participate in the pilot study. Two mothers from the seven that agreed to participate initially could not be interviewed, as one of the mother could not keep up to any mutually agreed date and time of interview due to personal reasons and the other had to cancel the interview due to her child’s ill health and felt too overwhelmed because of this to participate. The study had a final purposive sample of five mothers who had children aged between two and 16 years diagnosed with a developmental disability. The five participants were contacted by the researcher individually and through the group coordinator in an effort to run the study as a focus group at a mutually agreed date and time in the same venue where they met monthly. The researcher despite several attempts could not arrange a focus group meeting with the participants due to reasons such as unavailability of same time slots, different time commitments with children and a general lack of willingness towards participating in a focus group. The focus group could also not be conducted during one of the monthly meeting as agenda of these meeting had previously been planned with various outdoor activities for the families and children in those slots. In an attempt to overcome these barriers, the researcher offered the participants with offers of remuneration, travel expenses and a buffet lunch during the focus group but this was declined too. As a result of these practicalities, and also due to a preference shown by the participants it was decided to conduct one to one telephonic interviews as opposed to a focus group. The rationale for preferring focus groups over one to one interviews was based on various reasons. It was anticipated that this would be a quick and convenient way to collect data from several people simultaneously and more importantly promote group interaction by encouraging participants to talk to one another, ask questions, exchange anecdotes and comment on each other's experiences and points of view. However, as last resort, one to one interviews were conducted telephonically at a mutually agreed time. The implications of planning to use focus groups initially and gathering data through one to one telephone interviews has been explored in the discussion section of this chapter.

Data Collection:

Semi-structured interviews: As the self-help coping intervention is relatively novel in the area of parental stress it required a detailed output from the parents and hence it was considered appropriate to conduct ‘semi structured interviews’ to meet this aim. This form of interviewing was selected as a means of data collection for this study primarily because it is deemed suitable for exploring the perceptions and opinions of respondents and enables probing and clarification if required. Semi structured interviews also allow the researcher to gain all relevant information and clarification from the participants in regards to the preferences, acceptability, effectiveness, comprehensiveness, appeal and ease of usage etc. A semi-structured interview schedule / topic guide (Appendix B.3) was devised beforehand to ease the process following the procedure described by Smith (1996). This schedule consisting of the likely areas of questioning was informed by background literature and also by consultation with the research supervisor. The questions were initially framed following discussions with the research supervisor and were devised to elicit relevant information (Braun & Clarke, 2013) from participants which could help in gaining appropriate feedback regarding the self-help coping leaflet. The questions to begin with were designed to be broad and neutral, with the aim of putting the participants at ease at the start of the interview (Braun and Clarke, 2013). This sequence for the questions was carefully considered to provide a logical flow to data collection. The schedule acted as a guide for the researcher and outlined all areas of interest, for example, questions about the layout, language or ease of usage of the leaflet. It also mapped the possible ways in which the interview may proceed. A list comprising of prompts such as ways in which the leaflet can be improved was included to assist the participant to elicit further detail and explore particular aspects in greater detail where applicable. The schedule aimed to cover the areas of acceptability and usage of the leaflet and incorporated the following areas:

(i) Perception of the coping leaflet i.e. what the participants thought of the leaflet, whether it was considered helpful or not.

(ii) Effectiveness of techniques mentioned on the leaflet.

(iii) Suggestions of further improvement.

In order to confirm the general appropriateness of the devised schedule, a practice interview was conducted with an academic member of staff from the Department of Psychology, University of Wales Trinity Saint David. This allowed the researcher to test and refine the questions, and to practice her interviewing technique, thus greatly enhancing confidence prior to actual data collection. The topic guide was further refined after this interview but no major changes were made to the schedule based on this mock interview.

All the interviews for the present study were arranged at a day and time convenient for the participants and were conducted over the phone. Each interview was recorded using a digital recorder.

Data Storage: The interviews were audio recorded and transcribed within 24-72 hours of recording. All identifying information (names) were changed whilst transcription to ensure anonymity. Only the researcher and her supervisors had access to the recordings and transcriptions, which were kept in a secure place in the researcher's office on the university's premises. The recordings were deleted from the recorder within 48 hours of the interview taking place once they were uploaded to the computer on the university premises which is password protected. These recordings were deleted once all the data had been transcribed. Consent forms were stored in a separate locked and secure cabinet in the researcher's office separately from all other data.

Ethical Considerations

Ethical principles followed in this study have been discussed at length in Chapter Four. Clear ethical guidelines in relevance to this study were followed which include both the British Psychological Society's Code of Human Research Ethics and appropriate University guidelines. The study procedures as described below were given full ethical approval by the University of Wales Trinity Saint David Research Ethics Committee (Nov, 2015). The participants in this study had a freedom of choice in regards to their participation, withdrawal and use of the draft coping leaflet, the following section highlights the various ethical issues in relevance to this study:

Informed consent: According to the BPS Code of Human Research Ethics (BPS, 2014) researchers should ensure that every person from whom data are gathered for the purposes of research consents freely to the process on the basis of adequate information. Obtaining consent involves informing the participants about their rights, the purpose of the study, the procedures to be undergone, and the potential risks and benefits of participation. Potential participants in the present study were asked to read the Study Information Sheet (Appendix B.2) before consenting to participate in the study. The information sheet informed potential participants that a) participation is voluntary and b) that if they choose to take part that they are free to withdraw from the study at any time. Both written consent to participate in the study and verbal consent before the start of the interview were obtained for this study, as informed consent is not just a one-time event but a continuing process throughout a study, where the researcher must continue to provide information about participating in the study (Gupta, 2013).

Confidentiality: Subject to the requirements of legislation, including the Data Protection Act, information obtained from and about a participant during an investigation is confidential unless otherwise agreed in advance (BPS, 2014). To maintain confidentiality in the present study the participant names and identifying information were changed for the purposes of data storage and presentation. In an effort to maintain confidentiality, the participants were informed that their or if used by them during the interview their child's name will be anonymised whilst transcribing so that no information given can be identifiable to them. They were also informed that the audio recordings of their interviews will be deleted after transcription. All data that could lead to the identification of participants (e.g. participants' email addresses, telephone numbers but not consent forms) were destroyed as soon as the interview had taken place.

Collection of personal/sensitive information: There was a risk that taking part in the study may be potentially distressing to the participants. This was addressed by providing a lot of information beforehand about what taking part would involve and what the purpose of the designed leaflet is, so that potential participants could make informed decisions about their decision of getting involved in the study. Participants were also informed that could withdraw from the study at any time, without having to give a reason for doing so. Before the start of the telephone interview their right to withdraw at any point was explained again to make sure the participants knew that this option was open to them. The participants were also given an option of making contact with a stress management helpline if they experienced increased stress as a consequence of taking part in the study or using the coping leaflet.

Potential risks to the participants: Due to the nature of the study it was assumed that the participants may feel under pressure to use the draft coping leaflet everyday as a consequence of being part of a study or being a volunteer. However, it was made clear orally and in the written information provided, that the participation in the study was completely voluntary and that the participants were not obliged to use the coping leaflet in circumstances where they were unable to do so. However, the benefits of using the self-help coping leaflet were explained beforehand and the participants were requested to devote sometime to practice the techniques depending on when and where they can schedule time for it. There was no fixed minimum or maximum time to practice hence, participants were at free will to choose at their discretion.

Another risk to the participants was the potential of discomfort of using perhaps relatively new techniques of coping with distress. They were therefore informed to discontinue the use of any technique mentioned in the draft coping leaflet if they felt it was causing them any sort of discomfort in the first stance. However, if they wished to know more about any technique and wanted further information or guidance they were given the researcher’s contact details who could provide them with more information.

Potential risks to the researcher: The researcher did not face any significant potential risk due to the nature of this study, however, the only potential risk identified was that of distress which may occur if the parent being interviewed got too emotional or distressed. The protocol for the researcher in this situation was to politely culminate the interview and report this to the supervisory team and if the need be, contact a qualified counsellor who is a collaborator on this study.

Data analysis

The interviews were analysed using the 'thematic content analysis' approach, as it is an empirically driven approach for identifying, analysing, and reporting patterns (themes) within data (Braun & Clarke, 2006). One of the benefits of thematic analysis is its flexibility as it is not tied to any epistemological position and is therefore appropriate for this pragmatic mixed methods approach study (Fereday & Muir-Cochrane, 2006). It is considered to have an 'objective' epistemological positioning and unlike many other qualitative methods, studies utilising this approach have a minimal impact of the researcher's predispositions, and presence, on the emerging data (Harper & Thompson, 2012). Thematic analysis is a process of search for themes that emerge as being important to the description of a phenomenon (Daly, Kellehear, & Gliksman, 1997); it detects the most salient patterns of content in the data and clusters them as themes systematically as they appear.

Thematic analysis is considered as an appropriate method to elucidate the particular nature of a given group's conceptualisation of the phenomenon under study. This type of analysis may help to reveal something important about the data in relation to the research question or may refer to a specific pattern of meaning found in the data set (Braun & Clarke, 2006). Boyatzis (1998) suggests two levels at which themes can be identified using the thematic analysis approach: a semantic or explicit level, or a latent and interpretative level. Analysis at the latent level identifies and examines the underlying ideas, assumptions and conceptualisations and ideologies which inform the semantic content of the data. In contrast, a thematic analysis at a semantic level, identifies themes within the explicit or surface meanings of the data where the analyst is not looking for anything beyond what a participant has said or what has been written (Braun & Clarke, 2006). Braun and Clarke (2006), explain this difference by giving an example of an uneven blob of jelly, where the semantic approach would seek to describe the surface of the jelly, its form and meaning, while the latent approach would seek identify the features that gave it that particular form and meaning. For the present study, the data gathered was mainly to identify the strengths and limitations of the self-help coping leaflet and to identify it's acceptability amongst users, this was a relatively straightforward question and did not require interpretative work to identify broader meanings and implications. The analysis was hence conducted at a semantic level due to the nature of this research question which at this time point did not require an in-depth pursuit to identify ideologies or deeper meanings.

Transcription: Each interview was transcribed verbatim. With the aim to maintain the anonymity of the participants all identifying information was removed or changed. Following the transcribing, each transcript was subjected to a detailed systematic qualitative analysis using the Thematic Analysis approach. All interviews were analysed individually maintaining the following order as suggested by Braun and Clarke (2006):

Familiarising with the data: Braun and Clarke (2006) advise that if data collection happens through interactive means, the researcher possibly has some prior knowledge about the data and possibly some initial analytic interests or thoughts. They further suggest, that despite this it is vital for the researcher to immerse themselves in this data to an extent that they are well familiar with the depth and breadth of the content they are analysing, this can be done by repeated readings of the data in an active way looking for meanings. Following the transcription of all interviews, the researcher familiarised herself with the text. Notes were made for coding to signify initial analytic interests or thoughts.

Generating initial codes: Codes were then produced to identify features of the data (semantic) which appeared interesting for the purpose of this research. According to Boyatzis (1983, p. 63), codes identify a feature of the data (semantic content or latent) that appears interesting to the analyst, and refer to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon”. Coding in this instance was largely data driven due to the nature of the query and was done manually. The codes were initially identified and then matched with the data extracts from the interview to demonstrate the code.

Looking for themes: During this phase the data was analysed at the broader level of themes, rather than codes, the various codes generated in the previous step were sorted into potential themes, and then collated into relevant coded data extracts within the identified themes. These themes were defined based on the essence of what data it captured most consistently. Essentially, this step involved analysing the codes identified previously, and considering how these different codes may combine together to form an overarching theme.

Reviewing themes: After devising a set of themes they were reviewed to make sure that they are meaningful, clear and identifiable. As suggested by Braun and Clarke (2006), the themes were reviewed by collating extracts for each theme and considering whether they appear to form a coherent pattern. After establishing that the themes identified are meaningful and coherent with the data the results were collated and these are presented in the following section.

Results

The following section presents the main findings as they surfaced from the thematic analysis of the interviews. The themes identified describe the feedback of the mothers who used the coping intervention for nearly four weeks. The results revealed that as instructed by the researcher, the mothers engaged and used a range of coping strategies mentioned in the self-help coping leaflet. The feedback obtained from them on the appropriateness of the self-help coping leaflet indicated that this intervention may be an effective tool in mediating levels of stress and enhancing coping effectiveness amongst parents. The mothers also shared their views on how to improve the existing coping leaflet. The following are the main findings of the thematic analysis.

(i) Effectiveness of the techniques: All the participants in the present study tried either all or some of the coping techniques mentioned on the coping leaflet. When viewed as a whole, the mothers reported the leaflet as being a helpful tool in reducing their levels of stress. As Sian in the following excerpt illustrates:

Sian: yes, definitely, I think it is a very good idea telling people how to deal with their emotions really ... unless you do things like this it can get on top of you and… its overwhelming then if you've got so many things like I am saying you do need to get a way of you know organising your thoughts and not getting completely overwhelmed by it

When asked about the usefulness of the self-help coping leaflet, Sol explains:

Sol: I think it is a good idea you know like it says you know they were a couple there that I knew about sort of reminded about you know you may have read about them before or even done them before but to be reminded you know I am quite stressful quite often it would be you know a good resource to have. Yeah!

Ann, in a similar vein asserts that having a coping leaflet is a good idea; Ann: Yeah, It was a good idea, yeah a very good idea, and I've actually spoken to a few other parents about it and what I was doing and they said it was a good idea, so you know.

(ii) Variety of Coping techniques: The mothers also reported that it was a good idea of having a range of choices or options of coping strategies on the leaflet as it gave them a fair chance to try and then choose what worked best of them.

The various coping strategies mentioned on the leaflet were tried by all the mothers but the results indicated that there were differences in terms of their preference of which particular technique they found most effective. For example, some participants found that "taking time out" was an effective technique, whilst others thought that "writing things down" or "benefit finding" worked very well for them. For Ann, expressive writing worked better than the others.

Ann: The writing one…that was very positive because usually, sleeping is very difficult and I found that instead of it all going through in my head when I was writing it down I I was able to get back to sleep better.

Whereas for Sol focussing on the positive through finding benefits seemed to help more:

Sol: I suppose just sort of just trying to sort of forget about things which I we think about negative things and remember the positive things cause I do tend to be *quite negative so it's nice to actually sit there and try and remember the good things because that sort of makes you become more positive then doesn't it because when you think about positive things, it has a positive effect.*

All the mothers in this study reported that they found their chosen strategy effective in reducing their levels of stress and there was a likelihood of them continuing to use these techniques in the future to help them cope effectively. The study also revealed that the techniques were considered fairly simple and easy to use on a day to day basis. As Mariam points out she found the leaflet easy to use, helpful and simple.

Mariam: It has helped me so I guess I will keep going, it doesn't need a lot of hard work you see, I can do these things whenever I want wherever I want so there's no fuss about it, it's simple so I like it and so I will continue.

However, worry postponement as a technique was used only by two mothers reflecting a very low uptake of this technique.

Rebecca: I did not find this easy enough to understand how it works, I didn't practice it much honestly, it didn't seem very relevant to me. Sorry but, no this one didn't do it for me, all the others worked well as I could understand the principles behind them but I thought this one wasn't for me. I couldn't follow it I guess.

(iii) Suggestions on the design and layout: The participants made various suggestions regarding the design and layout of the coping leaflet. Though a majority suggested that they liked the content, sentences and words used in the leaflet, one of the participant commented that it might be useful for some parents to benefit from a simpler version which is less wordy and has more visual clues to explain the techniques mentioned.

Rebecca: I think it would be nice if you could add some pictures to it so it looks more beautiful, it's just an idea to make it look better, I would like it to be that way. For me the words were alright but I know of people who would think these are too many words on a paper so if you can do something about it that would be great

Most of the participants said that they liked the visual layout of the leaflet and found it easy to follow as Sol and Sian explain:

Sol: I think that was good I liked the fonts and the colours, its quite simple its not too sort of hard, I cant think of anything you change

Sian: I didn't have any problems with it… it was quite easy to follow … I didn't find anything too difficult. It seemed to be quite informally written and easy to understand. I'd imagine most people would be fine with it.

Other Suggestions: Two of the participants suggested that even though the coping leaflet is a good idea and a helpful resource in mediating their levels of stress, it would be a good idea if there can be a prompt or reminder for them to use the leaflet every day or every couple of days. As the intervention is a novel addition to their schedule and not a habit they suggested a reminder would be ideal for following or practicing the techniques on a more regular basis.

For example, Sol said: *I think it was sort of difficult to sort of remember and to look at it and sort of to basically just to remember to you know how to pay attention to it and to use the strategies basically…Possibly I suppose if there were sort of little alerts or little reminders ya maybe yeah… Ya I think the more you do it you know the more sort of normal and sort of everyday it'll just come naturally won't* *it but the beginning bit where you have to remind yourself to relax or you know sort of recognise that and then do something about it.*

The participants gave a reassuring opinion about the other information and explanation provided in the leaflet. They commented that it was particularly useful to have some examples of the techniques mentioned on the leaflet, such as counting backwards for distraction. The mothers also commented that it was useful that the leaflet acknowledged that not all techniques mentioned on it might be useful for them.

As Mariam pointed out : *The examples which explain whatever you mention on your leaflet are quite good, you see, they give a clearer picture because it's always easy to follow with examples, you know what to do. Like it says have a cup of tea or watch tele or do something else I quite like that…*

Future use/ online option: When asked about the likelihood of using the coping leaflet in the future the participants were unanimous in their response suggesting that they would continue the use of the techniques which they thought worked best for them to help them cope with their day to day stress.

Rebecca: Sure, definitely I would make use of it, I think it is a good way of giving time to yourself which I hardly ever do. I think I will go on with it, I have even told some of my friends I see at a different group about it and they think we should encourage each other to practice such things and also mindfulness

The participants were also asked if they would prefer an online version of the coping leaflet (accessible on their smartphone, tablet, or iPad etc.), most of them suggested that they would prefer the online version of the leaflet over the paper version as they can have access to it more easily and would not need to carry it around with them till they are accustomed to the techniques mentioned on the coping leaflet.

Mariam: For me it has to be on my phone, it will make it much easier, everyone uses their phones for everything really these days. I think I would tend to use it much more if I had it on my phone that would be good.

However, one of the participant suggested that she would prefer to have a paper version of the coping leaflet to refer to it as she only uses her phone occasionally and only for specific purposes of calling and texting.

Sian: I personally prefer paper I am a bit like that I don't use a phone , just for texting and .. I don't use it for the internet or anything so for me I think paper is fine…

Discussion

The aim of this exploratory study was to determine the appropriateness and the potential effectiveness of the coping intervention corresponding to the MRC phase I study for developing complex interventions. The results from this pilot study suggest that the processes, format and content of the self-help coping leaflet intervention were deemed acceptable to the present study population. However, there are certain limitations in this study which need to be identified and discussed in order to draw effective conclusions from this research.

The completion rates and positive responses to questions pertaining to the acceptability of this intervention provided evidence of approval. However, it needs to be considered that many groups which were initially approached by the researcher with the aim to recruit declined to participate in the study and it was considered unethical to ask them for reasons of declining. This echoes previous findings where concerns regarding participation by parents in studies is raised due to reasons such as general disinterest, lack of resources and awareness, and high care giving demands (Kerr et al., 2004; Pelentsov, Laws & Esterman, 2015). Another drawback was that all participants in this study were mothers of children with developmental disabilities (female), indicating an underrepresentation of men (n=0). This drawback as discussed in the previous chapter is a common occurrence in childhood disability studies, as it is mostly mothers who are the primary care givers and serve as mediators between the family, authorities, social contacts and medical practioners (Dabrowska, & Pisula, 2010; Gray, 2003; Meadan, Halle & Ebata, 2010). With the largest share of the care giving responsibilities for the child there is little doubt that mothers are more active participants in disability related research. It is apparent that men are under-represented in this study and this issue of an all-female participation is of importance, as the risk it poses is that of developing an intervention that may not be acceptable to men as their views have not been considered during development.

As this study is a part of a thesis, the themes emerging from the data collected were identified by only one person (the researcher) and the analysis was then validated by the study supervisor. Even though this process allowed for consistency in the method it failed to provide multiple perspectives from a variety of people with differing expertise. For a study of a similar nature, but in a different setting could potentially involve several individuals identifying an array of different themes' being developed using discussions with other researchers, a panel of experts, and/or the participants themselves (Guba & Lincoln, 1989; Lincoln & Guba, 1985). Another limitation of this study is voluntary participation as this may have resulted in self-selection of participants who are likely to be more interested and motivated to engage in a study of this nature (Robinson,2014). This motivation to be a part of a study which aims to benefit the study population in its aim may affect the results as the motivated participants may strive hard to get the desired results from any intervention that they may be using.

The sample size in this study is small therefore, generalizations may be limited, overall, the exploratory nature of this study and the small sample size prevent any firm conclusions being drawn. Also, the evaluation of the acceptability of this intervention was assessed through interviews only, which may have resulted in the Hawthorne Effect, which is the impact of the researcher on the research subjects or setting, notably in changing the participant's behaviour. In the present study it was more likely for the participants to comment about the positive aspects of the leaflet and its usage due to the rapport they built with the researcher. In order to minimise this, the researcher explicitly asked the participants about what their opinion was of the leaflet and if they had any ideas on further improvements or comments about something which they did not like or would like to be added to the leaflet. Other methods of evaluation such as the implementation of written feedback or free text responses need to be considered in future studies, with the aim to minimise the researcher's influence or bias to minimise the probability of false positive results.

In terms of the effectiveness of the self-help coping leaflet, results of this pilot study indicate that the leaflet was well accepted and may be regarded as a complex intervention as it comprises of a number of mechanisms which may potentially mediate levels of stress amongst parents caring for children with various developmental disorders. The strategies outlined on the self-help coping leaflet which constitute the components of this intervention, may work either solely on their own or may interact with each other leading to a markedly similar result in most cases, which is, a lower level of distress or effective use of coping mechanisms in parents using this intervention. Other components of the intervention such as the reassuring information and a variety of examples to choose from within a technique may also contribute to a reduction in stress. The results of this study also indicated a variability of outcomes such as in the chosen coping strategy, this is another dimension of this intervention which qualifies it as a complex intervention, which is its ability of causation of a number and variability of outcomes.

The results of the present study suggest that the provision of a self-help coping leaflet may be an appropriate and effective intervention for parents to mediate their levels of day to day parenting stress by promoting effective coping techniques. The participants anticipated that the coping leaflet can be a useful and handy tool for parents who are in a similar situation as theirs, having high levels of stress as a result of their caring role.

The mothers in the present study reported using a wide range of coping strategies from the coping leaflet to deal with their day-to-day levels of stress. Some of the mothers suggested that they had already used at least one of the techniques mentioned on the leaflet on previous occasions such as having a positive outlook towards life or writing a diary suggesting that they were proactively trying to deal with their stress even when they were not offered the leaflet. However, the mothers also noted that they found the techniques on the leaflet very useful and reassuring. They indicated that it would be a good idea to learn and practice coping techniques which were new to them and could help them to deal with their stress in a better manner.

All the mothers participating in this study reported that they found that ‘taking time out’ was an easy and effective coping technique. All the participants reported using it and finding it beneficial. The previous qualitative study (Study One) in this thesis indicated that the parents caring for a child with a disability suffered from exhaustion due to the constant demands of their caring role; a coping technique which encourages them to take some time off their role was perceived very positively amongst the mothers in the present study. Having time for one self where one can relieve stress is an effective coping mechanism (Hallum, 1995; Taanila, Syrjälä, Kokkonen & Järvelin; 2001) and when offered as an alternative was chosen as an effective coping mechanism by the participants in the present study.

Another technique of coping which the mothers found useful in this study was ‘benefit finding’. This technique helps an individual to remain motivated and sustain coping and well-being during difficult times by drawing on their beliefs, values and existential goals. The qualitative analysis of the previous study in this thesis also revealed that a few participants indicated that they try to appraise their situation of caring for a child with a disability in a rather positive light in an attempt to enhance meaning to their lives. Positive appraisal by means such as benefit finding results in an individual to employ cognitive strategies in order to reframe an existing situation to see it in a more positive light (Folkman & Mosokowitz, 2000). Literature suggests that looking for some benefits in the face of adversities can lead to a positive impact on well-being (e.g. Bonanno, Wortman, & Nesse, 2004; Ekas et al., 2015). The mothers reported that this was an easy and useful technique to help them cope better with their day-to-day stress.

Folkman (2008) also created a separate category for ‘infusing ordinary events with positive meanings’ as a form of meaning focused coping. The mothers in the present study mentioned that they used this form of coping (whilst discussing benefit finding) to experience more positivity in their lives. The genesis of positive moments from ordinary events is consistent with Tugade and Fredrickson's (2006) study which revealed that people have a tendency to feel good and prolong feelings of pleasantness. In the present study infusing positive meaning or finding benefits helps in better coping and growth in the mothers by deliberately infusing an ordinary event with a positive meaning to experience a positive moment, providing the 'breather' as hypothesised by Lazarus et al. (1980).

The coping leaflet also encouraged the participants to write down their feelings each day if they could, some of the mothers already used this method and confirmed that they found it useful in coping with their stress. This finding is consistent with research which indicates that the benefit of using writing as a coping mechanism is that it provides people with an opportunity to express their intrusive thoughts frequently, thereby diminishing the frequency of these thoughts in the long term (Pennebaker, 1989). Two of the participants said that they made use of this strategy and found it useful. Literature suggests, during stressful events, many people have an urge to express their feelings or thoughts related to the stressful event (Rime, 1995); this urge of expression may be associated with the comfort linked with the ventilation of stressful feelings or an attempt to make sense of a negative event (Lepore, 1997). Hence, writing is considered as an emotional expression promoting better coping for these dealing with long term stress.

An important finding in this study was that the participants did not use 'worry postponement' as a method of dealing with their stress. Only two of the participants suggested that they tried to use this technique but did not continue the use over a four-week period as they regarded other techniques on the leaflet more helpful. One of the mothers said that it was not an easy and simple strategy to follow. Upon reflection it is considered that the source of stress in this case is the condition or diagnosis of the child, this stress is long term and therefore postponement may not work as an ideal coping strategy for this group of parents.

Parents in the current study showed a preference for positive reappraisal (benefit finding), emotional expression (diary writing) and distraction (taking time out) in the current study. The already existing use of some of the techniques mentioned on the leaflet by participants also suggests that the intervention is an appropriate one for this population. In addition to the distraction techniques, participants found the information on the leaflet reassuring, for example, text on the leaflet suggesting that caring for a child with a developmental disability may be stressful seemed to reassure parents that they were not the only ones feeling anxious, or certain coping mechanisms may only work for certain individuals suggesting it is not a one size fit all situation when it comes to coping. Overall, the results of this study assessing the appropriateness of the self-help coping leaflet indicated that this intervention may be effective in minimising stress in parents of children with developmental disabilities.

Conclusion

Based on the participant feedback and results of the current study the following changes as suggested by the participants were made to the intervention:

The suggestion of worry postponement was removed from the final version of the coping leaflet.

It was agreed to send some form of polite reminders to the next group of participants who would participate in the study to remind them to use the coping leaflet every day.

Two picture clues were added with every coping suggestion.

The coping leaflet was printed on a coloured paper and laminated. (Appendix B.1 for draft Self-Help Coping Leaflet 1 and B.4 Self-Help Coping Leaflet revised version)

Despite its limitations, this study provided valuable data which informed the development of the next study (Chapter Seven). Additionally, the feedback about the coping leaflet provided valuable information regarding the further development of this intervention. Overall, the results indicated that the format and content of the self-help coping intervention were acceptable to the participants in this study. The results indicated that parents caring for a child with disabilities may benefit from this intervention as it was generally perceived positively by all the participants. However, there is a need to investigate the psychological impact of this intervention in terms of the levels of stress and its relationship to the coping mechanisms which people use and hence, the results of this pilot study will be used to inform the design and implementation of the next study in this thesis. The feedback about the leaflet will be used to further develop the intervention to improve its effectiveness and acceptability. Secondly, the combined results from this study and Study One (Chapter Five) will aid in identifying the outcomes and measures which need to be addressed whilst designing the next study.

CHAPTER 7

Study Three: The Evaluation of the Effectiveness of the Self-Help Coping Intervention

This chapter reports the exploratory trial of the effectiveness of the self-help coping intervention. As discussed in Chapter Four this study was informed by the Medical Research Council's (MRC) guidelines for the development and evaluation of complex interventions and represented a Phase II exploratory trial (MRC, 2000). According to the MRC framework (2000), and building on the continuum of increasing evidence from the previous study, this phase of evaluation stipulates that it should be able to provide information about the effectiveness of the intervention and assess the leaflet (intervention) in terms of its acceptability, usage and theoretically expected treatment effect (lower perceived stress and lower parental di10.stress). In addition to analysing the effectiveness of the intervention, this chapter also reports the theoretical analyses carried out to explore the theoretical predictors of stress in parents of children with developmental disabilities. As this is a longitudinal exploratory study over a relatively short timescale and with a small sample, a within subjects study design was considered appropriate (Bordens, & Abbott, 2002). The use of this design ensured that each participant could be observed repeatedly at different time points with the same measure, therefore giving a clear picture of any changes in outcome variables which might occur as a result of the use of the intervention in a relatively short period of time.

Aims of the study

The cumulative theoretical and empirical evidence established in the introductory chapter and the literature review (Chapter Two) and the results of Study One (Chapter Three) suggest that most parents caring for a child with a developmental disability report high levels of stress. Evidence discussed in Chapter Four advocates that the use of an effective self-help intervention for parents may provide opportunities to reduce day to day stress and encourage them to develop effective strategies to help manage daily stressors. Accordingly, the primary aim of this study was to examine the impact of the coping intervention on the key outcome measures of perceived stress, parental distress and ways of coping at baseline and after the use of the leaflet at two follow-up time points over the course of three weeks.

The specific objectives for this study were:

3. To explore whether the use of a self-help coping intervention will result in lower levels of perceived distress and parental stress over time.

4. To compare the impact of a self-help coping intervention on coping strategies.

The review of literature in Chapter Two and Three indicates that structured interventions may have a positive impact on parents caring for children with developmental disabilities. The self-help coping intervention explicitly aims at encouraging parents to develop effective strategies to help manage daily stressors and enhance their personal coping skills. The primary research hypotheses for this study were therefore:

1. The use of the intervention would result in lower levels of perceived stress from baseline to follow-up.

2. The use of the intervention would result in lower levels of parental distress from baseline to follow-up.

In the case of developmental disabilities, the diagnosis of the child's condition may not amenable to change. Literature in child disability studies suggests that with the passage of time most parents gain a certain level of expertise in practically managing their child's condition; however, they may need additional support in terms of addressing their emotions so they may be able to develop effective strategies to deal with day-to-day stress. As detailed in chapter Two, the self-help coping leaflet addresses this issue and promotes the use of active emotion coping techniques such as expressive writing and benefit finding which have been correlated with positive adjustment (Stanton et al., 1002). It also encourages the use of distraction to minimise stress (Bennett et al., 2007; Phelps et al., 2013) along with promoting the idea of the parents' taking time out for themselves exclusively. Therefore, it was also predicted that:

3. The use of the intervention would result in a higher use of active emotion coping.

The impact of the intervention on problem focussed coping was not studied as one of the main outcomes. The rationale behind this decision was that the nature of coping techniques promoted in the self-help coping leaflet were such that they were thought to have a minimal impact on problem focussed coping which is considered to be primarily task-oriented wherein attempts are made to do something to alter the source of stress. In the present study this source of stress is the diagnosis of the child which is not amenable to change and hence it was not considered that the intervention would have any impact on problem focussed coping. Similarly, avoidance strategies have been found to be effective when the stressor is immediate or short term (Roth & Cohen, 1986) which is not the case in present study. It was not considered that the encouragement to use active emotion coping would in any way affect the avoidance coping response in participants using this intervention. Hence, no hypotheses were formulated in relation to the use of the intervention and problem and avoidance coping.

Method

Design

The present study is a quantitative longitudinal exploratory intervention study, which aimed to assess the feasibility of the self-help coping leaflet. It was designed to study, a single sample over a short period to evaluate whether there were any changes in the coping responses of the participants after using the intervention (Streisand, Rodrigue, Houck, Pole & Berlant, 2000; Duncan et al., 2007). For the purpose of this study, it was decided to collect data both in the traditional paper format and the internet. The decision to use the internet was based around the premise that more and more people rely on it as a way of communication and also because of its efficacy as a tool for collecting data and decreasing the cost of recruiting a diverse sample (British Psychological Society, 2017;Hesse-Biber, & Griffin, 2013; Hewson, & Buchanan,2013; Kraut et al., 2004). Both methods (online and paper based) for data collection were used together in this research with the aim of reaching a higher number of participants.

Participants

The target participants for the present study were parents (mother or father) of children diagnosed with any developmental disability living in the UK. Participants were eligible to participate if they were a parent of a child with a diagnosis of a developmental disability and were able to give informed consent. Parents who chose to be a part of this study were given an option of choosing between the online and paper based version of the study. For parents choosing to participate in the online study, an important inclusion criterion was to have regular access to a smart phone or tablet. For parents choosing to participate using the paper-based version having access to the internet was not mandatory.

Exclusion criterion:

Parents who could not communicate in the mode of English were not deemed suitable for this study as all materials (paper and online) were delivered through the medium of English and it was important that the participants understand and answer questions in English without losing the essence of this information in literal translation.

Recruitment procedure

Initial advertising of study

Following ethical approval from the University, the study was advertised through the School of Psychology's (University of Wales, Trinity Saint David) official Twitter account (Appendix C.2), Cerebra (a charity dedicated to helping families with children with brain conditions)**,** Handsup for Downs, Carers UK and the Swansea Council for Voluntary Service**.** Recruitment was primarily undertaken via the Internet, with either posting web links to the online questionnaire on respective websites of organizations helping with recruitment or by hosting a link to a Facebook page providing information on the study. The 'Facebook' page provided details on the study and provided a link to the online and postal questionnaire. The study was advertised on the researcher's Facebook account too and was henceforth shared by various other colleagues and acquaintances on their social media accounts. It was also advertised by contacting various support groups throughout the United Kingdom, these were sent copies of the advertisement so they may put it in their newsletters and provide handouts to people using their services.

Recruitment and consent procedure

Upon seeing the study advertisement, the potential participants had the option of finding out more about the study by either following a link to the study information sheet or by getting in touch with the researcher by post who could then post the relevant study material to them in a paper format if they so wished. Upon reading the study information sheet online, the potential participants had an option of proceeding to participating in the study and filling in the consent form (Appendix C.3) before filling the online baseline questionnaire. It was ensured that potential participants were informed about the purpose of the research, how it was to be conducted, what was involved and the rights to withdraw in the study information sheet (Stevens, 2013). Potential participants were then required to agree to participating in the research by agreeing to all consent statements and finally by showing agreement to the statement that they agree to take part in this study. Participants also had the option of receiving information (leaflet, questionnaires) through the post or paper version for which they were guided to follow a separate link, which directed them to fill in a form with their address so a paper version could be sent out to them.

Final Sample

The study was advertised at two different time points in an effort to recruit more participants. In the first phase, the study was advertised and made live towards the end of October 2016, 24 people agreed to take part in the study at this time point. In a bid to increase the participant pool the study was re advertised on social media (Facebook) again in January 2017 resulting in 64 more participants signing up for the study and filling in the baseline questionnaire. All the participants completed the survey online, there were no requests made for the paper-based version.

Measures

Demographics (See Appendix C.4 for demographics)

At baseline, information on personal demographics was obtained, including age, gender, number of children, relationship with the concerned child, marital status, level of formal education and the time since diagnosis. In addition to the personal demographic information, the participants were also asked if they considered themselves to be a ‘single parent’ i.e. providing maximum care for their child by their own most of the time without having the opportunity of being able to share the caring responsibility with someone else.

The participants were also asked to provide demographic information about their child’s age and gender. However, none of these questions were mandatory as it was considered that some of the parents may be apprehensive to share this personal information with the researcher and it was their discretion whether to respond to these questions or not. Providing this information was not mandatory as a cautious approach not to put off any potential participants who may be reluctant to provide this information.

Parenting Stress Index Short Form (Abidin, 1995) (See Appendix C.7)

For the purpose of the present study the Parent Distress subscale of the Parenting Stress Index-4 short form (Abidin, 1983) was used. The PSI was originally designed to offer support to family clinicians for early identification and intervention by measuring the magnitude of stress in the parent-child system. It consists of 101 items giving a cumulative score of parenting stress. The PSI is considered to have strong properties (Haskett et al., 2006), however, it is a lengthy instrument and the assessment time can be a prohibitive factor. As a result, Abidin (1995) developed a shorter version the PSI consisting of 36 items based on factor analyses of the PSI and identified three main domains in the scale as Difficult Child (DC), Parental Distress (PD), and Parent–Child Dysfunctional Interaction (PCDI) with internal reliability coefficients of (Cronbach’s alpha) of .80 to .87 for the three subscales. (i) The Parental Distress subscale measures the distress a parent feels due to personal factors related to parenting, such as the extent to which parents feel competent, restricted, conflicted, supported, or depressed in their role as a parent. (ii) Parent–Child Dysfunctional Interaction subscale assesses whether the parent perceives his or her interactions with the child as either positive (i.e., reinforcing) or negative (i.e., unsatisfying). It reflect the parent’s stress based on (i) the parent’s dissatisfaction with their child’s interaction (e.g. child smiles at me less than expected or child doesn’t giggle or laugh much when playing). (iii) The Difficult Child subscale measures behavioural characteristics of the child that make him or her easy or difficult to manage, due to either temperament and/or noncompliant, defiant, or demanding behaviour. It measures the parent’s perception of their child’s abilities (e.g. child is moody and easily upset); these subscales tend to focus more on the characteristics of the child and are to a very large extent dependent on the severity of the child’s diagnosis. The intervention in this study will not be able to influence or alter these domains (PD, PCDI) being child specific hence they were not included as a measure.

The PSI-SF has been used to measure parenting stress in a number of studies (e.g. Anat Zaidman-Zait et al, 2010; Hassall et al., 2005; Smith et al, 2001). This scale has also been used for measuring stress in parents of children with developmental disabilities (e.g. Chadwick et al., 2001; Drew et al., 2002; Salt et al., 2002). The PSI-SF has shown high internal consistency and adequate test–retest reliability and has been used widely in studies of parents of children with disabilities. The PSI-SF also has high coefficient alpha reliabilities at .91 for the Total Stress subscale, .87 for the Parental Distress subscale, .80 for the Parent – Child Dysfunctional Interaction subscale, and .85 for the Difficult Child subscale (Abidin, 1995). The total stress score on the full-length PSI correlated at .94 with the PSI-SF (Abidin, 1995). In the current study, the Cronbach alpha coefficient at baseline was .87 for the Parental Distress subscale.

Perceived Stress Scale (PSS-10) (Cohen et al., 1983; Cohen and Williamson, 1988) (See Appendix C.5)

In order to measure the perception of stress in parents the Perceived Stress Scale (10 item version) developed by Cohen and Williamson (1988) was administered. This scale is a self-report instrument based on Lazarus's theory of stress appraisal (Lazarus, 1966; Lazarus & Folkman, 1994).

The Perceived Stress Scale (PSS) is a psychological instrument designed to measure an individual’s perception of stress, it aims to measure “the degree to which an individual perceives aspects of their lives as unpredictable, uncontrollable, and overloaded” (Cohen, 1986, p. 716). The PSS takes into consideration the personal and contextual factors that influence the various degrees to which a person may view a situation as stressful. The PSS-10 has been used in a number of studies to measure stress in a broad range of population (e.g Cohen et al., 1993; Himelstein et al., 2012; Losada-Baltar, 2005; Remor & Carrobles, 2001; Tehee et al., 2009). This scale has also been used for measuring stress in parents of children with developmental disabilities (e.g. Giallo & Payne, 2006; Skok, Harvey & Reddihough, 2006).

There are two versions of the PSS, the 14 and10 item version. Cohen and Williamson (1988) developed the PSS10. The original version had 14 items asking participants to rate their stress over the past month, with seven items negatively stated and seven items positively stated. The first short form which has been used in the current study has ten items, six of which are negatively stated and four positively stated.

Phrasing of questions

For the purpose of the current study the original stem of the questions at Time two and Time three was changed from 'In the past month' to 'since receiving the coping leaflet' due to the questionnaire being used at somewhat different time points. No alterations whatsoever were made to the Baseline questionnaire.

Scores are obtained by reversing responses (0 = 4, 1 = 3, 2 = 2, 3 = 1 & 4 = 0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. The score ranges from 0-40, the maximum PSS score of 40 indicates the highest level of stress (Cohen, Kamarck, & Mermelstein, 1983; Cohen & Williamson, 1988; Khalili et al., 2017; Taylor, 2015), 0-13 indicates a low stress score and the scores ranging from between 14-26 are average stress (https://das.nh.gov/wellness/docs/percieved%20stress%20scale.pdf). Cohen & Williamson (1988) resisted the idea of the PSS as being a diagnostic measure, but recommended the PSS-10 as a means of identifying individuals at risk for worsening conditions, and as a means of tracking an individual's response to an intervention (Roberti et al., 2006).

The PSS-10 has been established as a psychometrically reliable, valid, and economical tool. Specifically, the internal consistency of the tool has been reported as relatively high (Cronbach's α = 0.78), (Cohen & Williamson, 1988; Olpin, 1996). In a systematic review of 19 studies using the three versions of the PSS (14, 10 and 4), Lee et al., (2012) evaluated the Craonbach's alpha of the PSS-10 at >.70 in all 12 studies in which it was used. The test-retest reliability of the PSS-10 was assessed in four studies, and met the criterion of >.70 in all cases. In the current study, the Cronbach's alpha coefficient at baseline was .89.

Brief Coping Orientation to Problems Experienced scale (BRIEF-COPE) (Carver, 1997). (See Appendix C.6)

The original Coping Orientation Problems Experienced scale (COPE) developed by Carver et al., (1989) is a multidimensional coping inventory to assess the different ways in which people respond to stress. Five scales (of four items each) measure conceptually distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support). Five scales measure aspects of what might be viewed as emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measuring coping responses that arguably are less useful (focus on and venting of emotions, behavioural disengagement, mental disengagement).

The Brief COPE was chosen over other coping measures as it encompasses a broad range of coping strategies and can be presented in a situational format allowing the flexibility to explore coping specifically associated with the caring demands of a child with a disability and the use of the coping leaflet. The Brief COPE is also shorter and hence quicker to administer in comparison to the original version of the COPE. This scale measures 14 theoretically identified coping responses: Self-distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioural disengagement, Venting, Positive reframing, Planning, Humour, Acceptance, Religion, and Self-blame. For the purpose of this study coping responses have been divided into three categories that of active emotion, problem and avoidance focussed coping (e.g. Endler & Parker, 1994; Hastings et al., 2005; Kashdan, Barrios, Forsyth, & Steger, 2006). Active emotion coping includes responses which are adaptive and aim to manage the intensity of the stress by acknowledging, addressing and understanding one’s emotion, for example, positive reframing and acceptance. Problem focussed coping deals with responses indicative of efforts being made by an individual to address the stress, for example, planning and use of instrumental support; and avoidance coping constitutes of coping responses which are dysfunctional such as substance misuse or self-blame.

Several authors have distinguished emotion and problem focused coping (Folkman, 1984; Lazarus & Folkman, 1985) whilst the others distinguish between active emotion and avoidant coping strategies (Coyne & Racioppo, 2000; Holahan & Moos, 1987). Brown and Nicassio (1987) argue that emotion-focused strategies should be considered as separate dimensions of positive (active) coping and avoidance (passive) coping to enable researchers to isolate these dimensions for better results. Hence the use of active emotion coping and avoidant coping should ideally be evaluated separately in terms of coping effectiveness. It was considered relevant to divide further the emotion focused items of the Brief COPE, in order to achieve meaningful conclusions so that such diverse items (for example: I've been saying to myself "this isn't real.”; I've been trying to see it in a different light, to make it seem more positive. Or, I’ve been blaming myself for things that happened.) are not used to operationalize a single construct (emotion focused). (Please refer to Appendix D.2 for a table of the items combined to make problem focused, active emotion and avoidance focused coping).

The phrasing of the items has not been altered; however, the anchoring statement for the Brief COPE at Time two and Time three requested the participants to answer statements keeping under consideration the time since they received/used the coping leaflet.

Scoring:

Items are rated on a 4-point Likert scale, ranging from 1 “I haven’t been doing this at all” to 4 “I’ve been doing this a lot”. Each of the 14 scales is comprised of 2 items; total scores on each scale range from 2 (minimum) to 8 (maximum). Higher scores indicate increased utilization of that specific coping strategy. Total scores on each of the scales are calculated by summing the appropriate items for each scale. No items are reverse scored. There is no overall total score, only total scores for each of the scales. Coping styles are categorized for comparison of results (i.e problem-focused vs. active emotion-focused coping, and avoidant coping styles). The data from this measure will be examined to analyse to examine if there is a variation in the coping styles used by parents after using the coping leaflet. It was also aimed to find out if there is a relationship between levels of stress and the use of specific coping techniques.

The Brief COPE has been used in a number of studies to assess a broad of coping strategies in a broad range of populations including parents of children with disabilities (e.g. Benson, 2009; Hastings et al., 2005; Ingersoll & Hambrick, 2011; Meyer, 2001; Wong & Heriot, 2008) and has been established as a psychometrically reliable and valid construct. Internal consistencies have been reported as good for emotion-focused, problem focused, and dysfunctional subscales (Cronbach’s α 0.72, 0.84, and 0.75), (Cooper, 2008). Internal reliabilities for the 14 subscales in the Brief COPE range from α = 0.57- 0.90 (Carver, 1997), and complementary results have been established with a population of parents of children diagnosed with autism (α = 0.54-0.93) (Benson, 2009). For the present study, the Cronbach’s alpha coefficients were .81, .71 and .57

for problem-oriented coping, avoidance-oriented coping and active emotion-oriented coping respectively.

Process Measures

In order to assess the usage of the leaflet, the participants were asked for additional information at Time two (one week after the receipt and use of the intervention) and Time three (two weeks after the use of the intervention). This included questions measuring the frequency of the use of the leaflet in terms of number of days it was used and time spent practicing each technique. The participants were also asked to specify the techniques which they practiced during this time. There was also a question included at Time two for the participants to rate the coping techniques based on their perceived effectiveness.

Open-ended questions In order to allow participants to expand on any answers should they wish so, they were given an option to provide their feedback about the self-help coping leaflet and their experience using it at Time two and Time three through free text boxes.

Procedure: ***Delivery of intervention*** (Appendix C.1, B.4 for process flowchart and final version of the coping leaflet respectively). The intervention was only introduced to the participants who consented and completed the baseline assessment. These participants were given the option of receiving either an online pdf version of the intervention or a laminated paper version. 30 participants chose to receive the laminated paper version of the leaflet. Participants were encouraged to engage in the intervention for a week each time before they were assessed at Time two and Time three respectively. As a reminder for the participants to make use of the intervention, they were sent one text message as a reminder per week whilst they were a part of the study. It was hoped that this reminder would prompt the use of the leaflet. This was done by the researcher only if they had provided their telephone number and given consent for receiving one text per week to remind them of using the intervention. Text messages were also sent to participants requesting them to fill in the questionnaires once each week for two weeks.

Data Collection

For the purpose of data collection, a web based survey software; SurveyGizmo (https://www.surveygizmo.com/) was used to collect data online through self-administered questionnaires at three different time points. No requests were made for a paper-based version of the study information or questionnaires. Data collection at Time 1 was at baseline, this was pre-intervention when the participant signed up for the study. Time 2 data was collected approximately after the use of the intervention for one week. Time 3 data was collected approximately one week after Time two questionnaire was completed (Time 3). However, the time of completing surveys at Time 3 and Time 2 varied considerably between participants as the researcher had to wait for participants to complete the Time 2 questionnaire before sending them a link to the last questionnaire.

Assessment at Time 1 (Baseline) The baseline questionnaire could be accessed online immediately after reading the study information sheet and filling in the consent form. Participants were requested to read the study information sheet, provide consent and proceed to fill in the questionnaires which included demographic information at baseline. Following completion of the baseline questionnaire participants were sent a copy of the coping leaflet either in a paper format or a pdf version based on their choice.

Assessment at Time 2 Approximately a week after sending them the coping leaflet, a link to the Time two questionnaire was emailed for the participants to complete. Participants also received a text reminder during this week to use the coping intervention.

Assessment at Time 3 After the participants submitted the Time two questionnaire they were sent a link to the last questionnaire via email a week after the completion of the second questionnaire. The participants were again sent a text reminder to use the coping leaflet and complete the survey if they had agreed to the option of receiving a reminder. At completion, they were thanked for their participation and were given the researcher’s contact details if they wished to know more about the study.

Ethical Considerations: Broader ethical principles have been discussed at length in Chapter Four of this thesis. The following section discusses specific ethical considerations of relevance to this study:

For the present study, ethical guidelines have been followed which include both the British Psychological Society (BPS) Ethics Guidelines for Internet-mediated Research (2017) and BPS Code of Human Research Ethics (2014) as well as appropriate University guidelines on data storage (Guiding Ethical principles, n.d). The University of Wales Trinity Saint David Research Ethics Committee gave full ethical approval to the study (Study three ethical approval received May 2016).

Informed Consent

In accordance with the code of ethics outlined by the BPS (2014), the longitudinal nature of the study, the amount of time required for participation, the right to withdraw at any time, the researcher's contact information and an assurance of confidentiality were given to potential participants through the study information sheet prior to the commencement of data collection. Participants were asked to provide an online consent after they read the study information sheet. This is described as a common and legitimate way of obtaining informed consent in questionnaire-based research since no unreasonable risks were involved (Stein & Cutler 1996). The participants could have access to the questionnaire only after providing consent.

Confidentiality

To maintain confidentiality, participants' names and other identifying information were changed for data presentation. All quantitative data were collected anonymously through SurveyGizmo and subsequently stored in an electronic document for confidentiality purposes. All published data from the study were anonymised in accordance with the Data Protection Act 1998. The participants names were allocated with an identification code at the start of the trial and these numbers were used to identify and gather data for each participant to ensure that their data is not associated with their name but rather their identification code or participant number. Names of participants were not used with any data and only unique identification codes were used to identify participants. The online questionnaire data captured through the Survey Gizmo tool used firewalls and encryptions that protect information from hackers or malware.

Potential risks to the participants

Due to the nature of the study it was assumed that the participants may feel under pressure to use the draft coping leaflet everyday as a consequence of being part of a study or being a volunteer. However, it was explained in the study information sheet that the participation in the study was voluntary and that the participants were not obliged to use the coping leaflet in circumstances where they were unable to do so. However, the benefits of using the leaflet were explained beforehand and the participants requested to devote sometime to practice the techniques depending on when and where they could schedule time for it. There was no fixed minimum or maximum time to practice hence; participants were at free will to choose at their discretion.

Data Storage

Data for this study was collected online (as all the participants chose this option). It was downloaded into SPSS for the purpose of analysis and to follow good practice was saved on a shared private one drive with password protection. The data was stored anonymously with a unique identifying code on a password-protected university computer and backed up on a hard drive stored securely with the researcher. After completion of the study no participant data was identifiable to the individual. Consent forms were stored securely separately from all data.

Data Analysis

Descriptive statistics

These (means, standard deviations, and frequencies) were used to describe the basic features of the data in this study with the aim of providing simple summaries about the participants' demographic and psychosocial characteristics such as gender, age, level of education, number of children and marital status of the parents; and, the gender and time since diagnosis of the concerned children. The flow and retention of participants through the study were also analysed using descriptive statistics.

Participation bias

Independent samples T-Tests (x3) were used to identify any significant differences in the levels of perceived stress, parental distress or coping orientations (dependent variables) between those who dropped out of the study after completing the baseline assessment (Time 1) and those who completed Time 2 follow-up questionnaires (categorical independent variables).

Main Analysis: Effectiveness of the intervention

With the aim of exploring the effectiveness of the intervention on the key outcomes of perceived stress, parental distress and orientation towards active-emotion coping and avoidance coping a series of one-way analysis of variance (ANOVA) tests were conducted.

One-way repeated measures ANOVAs were conducted to compare the scores on perceived stress, parental distress, avoidance and active emotion coping at baseline, one week after using the intervention and two weeks after using the intervention. This allowed the analysis of the same participants (within subjects) under different points in time based on their use of the intervention (Time 1, Time2 and Time 3). The dependent variables (continuous) were: (i) perceived stress, (ii) parental distress and orientation towards (iii) active emotion coping and (iv) avoidance coping. The independent variable (categorical) for conducting each analysis of variance (i, ii, iii and iv) was Time (x3).

Factor Analysis:

In order to assess the robustness of the factors within each sub-scale the 28 items of the Brief COPE were subject to principal components analysis (PCA) using SPSS version 25. The factor analysis allowed to reduce the number of related variables by identifying groups among the intercorrelations of a set of variables (Pallant, 2016) and thereby reducing the variables to a more manageable number prior to using them in an analysis of variance.

ANOVA on the nine sub-scales identified by Factor Analysis

In order to explore whether the use of the intervention had any impact on the type of coping strategies used across the nine facets of coping identified through the Factor Analysis, a series of one-way repeated measures ANOVA were conducted to compare coping scores on each of these subscales at Time 1, Time 2 and Time 3. The independent variable (categorical) for conducting the analysis of variance was Time (x3); and the dependent variable (continuous) was the coping score on each of the nine subscales of coping identified by the factor analysis.

Analysis II: Theoretical predictors of stress

With the aim to predict if coping orientations and parental distress make independent contributions to perceived stress an exploratory analysis exploring predictors of stress in parents of children with developmental disabilities was conducted at baseline (it was not possible explore predictions over time due to the small sample size with the follow-up data).

Correlations between variables

The relationship between perceived stress (as measured by the Perceived Stress Scale) and problem focussed coping (as measured by the Brief COPE scale) was investigated using Pearson product-moment correlation coefficient at baseline. The relationship between perceived stress, parental distress and the demographic variables was also investigated using Pearson product-moment correlation coefficient at baseline as a part of checking assumptions prior to conducting the regression.

Standard Multiple regression analysis

After establishing the relationship between coping and perceived stress through the correlational analysis, a standard multiple regression was conducted at baseline to evaluate each independent variable (type of coping response and parental distress) in terms of its predictive power and unique variance over and above that offered by all other independent or predictor variables on the dependent variable i.e. perceived stress. The predictor (independent) variables for this regression were: parental distress, avoidance coping, active emotion coping and problem focused coping. This predictive analysis would identify the strength of the effect that the independent variables have on a dependent variable and indicate how this set of variables is able to predict perceived stress and also how much unique variance of each of these independent variables explains in the dependent variable over and above the other independent variables included in the set. This analysis would also allow to establish how much will the dependent variable change on changing the independent variables, for example, will a decrease in the use of avoidance coping (independent) predict lower perceived stress (dependent).

Leaflet usage

In order to gauge the usage of the coping leaflet at Time two and Time three, the frequencies of the process measures was analysed. Thereafter, qualitative content analysis was used to analyse the comments and feedback provided by various participants at Time two and Time three with the aim of identifying any common concerns and experiences regarding the self-help coping leaflet.

Frequency of leaflet usage and stress:

An independent samples t-test was conducted at time two to determine if there was any difference between the levels of perceived stress (continuous dependent variable); and, the frequency of usage of the self-help coping leaflet (categorical independent variable). This analysis was conducted at time two because the leaflet was not used at baseline (time one) and the number of participants in the study at time three was significantly less.

Results

This section describes the results of the statistical analyses, including descriptive statistics generated to describe the nature of the sample and those considered as relevant to the main research questions. To maintain focus of the study, only associations of interest with the study aims are presented in the body of the text.

Recruitment and Respondent Profile

Of the respondents, 83 (94.3%) were female who described themselves as mothers and five (5.7%) were male, who classed themselves as fathers of a child with a developmental disability. The age of the respondents ranged from 20 to 58 with a majority 53.4% (n= 47) falling within the age group of 35-44 years. 42 (47.7%) participants in the study were educated to a university degree or higher level of education with only two participants with no formal qualifications. A majority of the study participants were either married or cohabiting with a partner 78.5% (n= 69). A majority of the participant population (n= 77) 87.5% had between one to three children, and half of the total participants had received a diagnosis for their child within the last five years. In terms of distribution of the child's gender, there were more boys (n= 56) 63.6%, as compared to, girls (n=30) 34.1% diagnosed with a developmental disability in the present study sample. Forty three (48.9%) participants considered themselves as a single parent in terms of caring responsibility towards their child. (Appendix D.3)

Figure 2.1 depicts the flow and retention of participants through the study. At baseline (Time one) 88 participants took part in the study over a four month period. Recruitment commenced in late October 2016 and continued up to the middle of January 2017 for baseline participants. 42.05 percent of the participants completed the study post intervention (Time two) with only 23.86 percent of the baseline (56.76 of Time two) completing all three questionnaires at Time three.

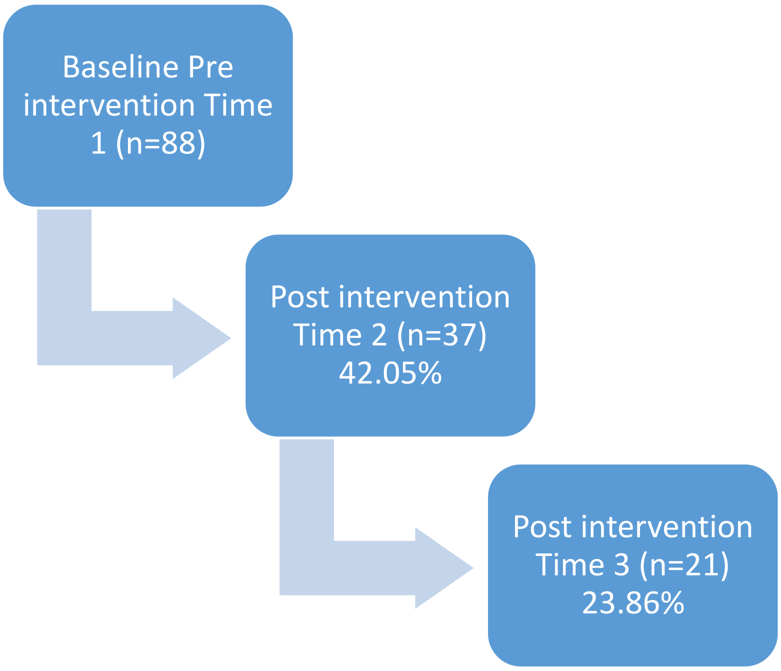

Figure 2.1 Participant flow throughout the study period.

Participation bias

In order to explore whether there were any differences in the levels of stress between those who dropped out of the study after completing the baseline assessment (Time 1) and those who completed follow-up questionnaires, the perceived stress scores as measured by the PSS of participants who dropped out of the study after completing the baseline assessment were compared with those who went on to complete Time 2 questionnaires. Of the 88 participants who completed their Time 1 assessment, 37 (42%) completed the Time 2 questionnaire. Independent samples T-Test explored the differences between the Time 1 drop outs and Time 2 completers. There was a significant difference in perceived stress scores for drop outs (M = 23.29, SD = 5.89) and completers at Time two, M = 26.84, SD = 6.22; t (86) = -2.71, p =.02. The magnitude of the differences in means (mean difference = -3.55, 95% CI: -6.13 to -.95) was moderate (eta squared = .08). There were no significant differences in completers and drop outs on measures of parental distress or coping orientations.

There were also no significant differences in the baseline demographic characteristics of participants who dropped out after the baseline assessment. It was concluded in line with established cut-offs (Cohen, Kamarck, & Mermelstein, 1983; Cohen & Williamson, 1988; Khalili et al., 2017; Taylor, 2015), participants with a high stress score based on the PSS (mean, 26.84) opted to stay in the study and try the coping leaflet as opposed to participants with an average stress score based on the PSS (mean, 23.29) who dropped out of the study after completing the baseline questionnaire. Previous studies using the PSS with parents of children with developmental disabilities report similar findings with most parents falling in the high stress category (e.g. Bazzano et al., 2013; Skok, Harvey & Reddihough 2006).

Main Analysis: Effectiveness of the intervention

In order to explore the effectiveness of the intervention on the key outcomes of perceived stress, parental distress and orientation towards active emotion coping and avoidance coping a series of one way analysis of variance tests was conducted.

Hypothesis 1 In order to test the hypothesis that the use of the intervention would result in lower levels of perceived stress from baseline to follow-up a one-way repeated measures ANOVA was conducted to compare the scores on Perceived Stress at Time 1 (baseline, prior to intervention), Time 2 (one week after the intervention) and Time 3 (two weeks after the intervention. The means and standard deviations are presented in Table 1.3

There was a significant effect for time, Wilks' Lambada = .35, *F* (2, 21) = 17.56, *p* < .001, multivariate partial eta squared = .64. Post hoc tests (Bonferroni) revealed that the levels of perceived stress were significantly higher in participants at Time 1 (*p* = .003) in comparison to participants at Time 2 and Time 3. Stress scores of participants at Time 2 and Time 3 did not differ significantly (*p* = .053). Hence, the null hypothesis is rejected.

Table 1.3

Means and Standard Deviations on the measure of Perceived Stress at Time 1, Time 2 and Time 3. On final sample (N=21)

Time	*n*	*M*	*SD*
Perceived Stress t1	21	26.05	6.89
Perceived stress t2	21	19.24	6.08
Perceived stress t3	21	17.19	6.12

Hypothesis 2 In order to test the hypothesis that the use of the intervention would result in lower levels of parental distress from baseline to follow-up. A one-way repeated measures ANOVA was conducted to compare the scores on Parental Distress at Time 1 (baseline, prior to intervention), Time 2 (one week after the intervention) and Time 3 (two weeks after the intervention. The means and standard deviations are presented in Table 1.4 There was a significant effect for time, Wilks' Lambada = .33, *F* (2, 21) = 19.28, *p* < .001, multivariate partial eta squared = .67. Post hoc tests (Bonferroni) revealed that the levels of perceived

stress were significantly higher in participants at Time 1 ($p < .001$) in comparison to participants at Time 2 and Time 3. Stress scores of participants at Time 2 and Time 3 did not differ significantly ($p = 1$). Hence, the null hypothesis is rejected.

Table 1.4

Means and Standard Deviations on the measure of Parental Distress at Time 1, Time 2 and Time 3.

Time	*n*	*M*	*SD*
Parental Distress t1	21	44.86	9.87
Parental Distress t2	21	20.19	10.79
Parental Distress t3	21	20.24	9.30

Hypothesis 3

In order to test the hypothesis that the use of the intervention would lead to a significant increase in the use of active emotion coping a one-way repeated measures ANOVA was conducted. There was no significant relationship between the intervention and active emotion coping. However, a significant effect was noted on the use of avoidance coping. Wilks' Lambada = .33, F (2, 21) = 19.18, p <.001, multivariate partial eta squared = .66. The means and standard deviations are presented in Table 1.5 Hence the hypothesis, that the use of the intervention would result in a higher use of active emotion coping is rejected.

Table 1.5

Means and Standard Deviations on the measure of Avoidance Coping at Time 1, Time 2 and Time 3.

Time	*n*	*M*	*SD*
Avoidance coping t1	21	15.48	3.37
Avoidance coping t2	21	12.10	2.25
Avoidance coping t3	21	11.48	2.37

Based on the results of the main analysis exploring the effectiveness of the intervention it can be concluded that the levels of perceived stress reduced significantly between time one and time two, suggesting that the intervention may be an effective tool in reducing stress in parents of children with developmental disabilities.

Factor Analysis:

In order to assess the robustness of the factors within each sub-scale the 28 items of the Brief COPE were subjected to principal components analysis (PCA) using SPSS version 25. Prior to performing PCA, the suitability of data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of many coeffecients of .3 and above. The Kaiser-Meyer-Olkin value was .61, close to the recommended value of .6 (Kaiser, 1970,1974) and Bartlett's test of Spherecity (Bartlett, 1954) reached statistical significance, supporting the factorability of the correlation matrix.

Principal components analysis yielded nine components with eigenvalues exceeding 1, explaining 74.1% of the total variance and 17.8%, 11.7%, 9.7%, 8.8%, 6.9%, 6.3%, 4.7%, 4.4% and 3.8% of the variance respectively. An inspection of the screeplot (Appendix D.4) revealed a clear break after the ninth component. Using Catell's (1966) scree test, it was decided to retain nine components for further investigation. These nine components are (1) Active coping and planning, (2) Self-blame and venting (3) Emotional and Instrumental support (4) Religion and acceptance (6) Substance use (7) Positive reframing (8) Denial and (9) Self-distraction. (Please refer to Table 1.6 and 1.7 for pattern and structure coefficients).

Table 1.6 PCA of the Brief Cope items (Pattern coefficients)

	1	2	3	4	5	6	7	8	9
I've been concentrating my efforts on doing something about the situation I'm in	**.812**								
I've been taking action to try to make the situation better	**.806**								
I've been trying to come up with a strategy about what to do	**.803**								

I've been thinking hard about what steps to take	**.765**					
I’ve been trying to get advice or help from other people about what to do	**.439**	.388				**.431**
I've been accepting the reality of the fact that it has happened	.382		-.361			
I've been using humour to deal with the situation		**-.896**				

I've been using humour to make the situation light	**-.892**		
I've been trying to find comfort in my religion or spiritual beliefs		**-.925**	
I've been praying or meditating		**-.883**	
I’ve been blaming myself for things that happened			**.794**
I’ve been criticizing myself			**.733**

I've been saying things to let my unpleasant feelings escape		**.686**	
I've been expressing my negative feelings		**.634**	
I've been giving up the attempt to cope	-.303	**.585**	
I've been giving up trying to deal with it		.398	
I've been using alcohol or other drugs to make myself feel better			**.944**
I've been using alcohol or other drugs to help me get through it			**.927**

I've been getting emotional support from others	**.895**	
I've been getting comfort and understanding from someone	**.837**	
I’ve been getting help and advice from other people	**.725**	
I've been saying to myself this isn't real		**.842**
I've been refusing to believe that it has happened		**.797**

I've been turning to work or other activities to take my mind off things				**.703**
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping		.349	-.303	**.510**
I've been learning to live with it	-.388			**-.405**

I've been trying to see it in a different light, to make it seem more positive	**-.916**
I've been looking for something good in what is happening	**-.794**

Extraction Method: Principal Component Analysis. Rotation Method: Oblimin with Kaiser Normalization.

Table 1.7 PCA of the Brief Cope items (Structure coefficients)

	Component								
	1	2	3	4	5	6	7	8	9
I've been taking action to try to make the situation better	**.839**								
I've been trying to come up with a strategy about what to do	**.812**								-.323

I've been concentrating my efforts on doing something about the situation I'm in	**.790**		
I've been thinking hard about what steps to take	**.784**		-.313
I've been using humour to make the situation light		**-.911**	
I've been using humour to deal with the situation		**-.905**	

I've been trying to find comfort in my religion or spiritual beliefs			**-.917**						
I've been praying or meditating			**-.866**						
I've been learning to live with it			**-.504**					**-.456**	**-.451**
I've been accepting the reality of the fact that it has happened	**.412**		**-.448**						-.338
I’ve been blaming myself for things that happened				**.806**					

I’ve been criticizing myself	-.301	**.727**				
I've been saying things to let my unpleasant feelings escape		**.679**				
I've been giving up the attempt to cope	-.310	**.647**		.345		.328
I've been expressing my negative feelings		**.638**			.304	
I've been giving up trying to deal with it	**-.462**	**.507**	.336			.399
I've been using alcohol or other drugs to make myself feel better			**.942**			

I've been using alcohol or other drugs to help me get through it		**.923**	
I've been getting emotional support from others			**.860**
I've been getting comfort and understanding from someone			**.825**
I’ve been getting help and advice from other people	.328		**.765**

I’ve been trying to get advice or help from other people about what to do	**.552**	**.419**				**.565**		
I've been saying to myself this isn't real							**.834**	
I've been refusing to believe that it has happened							**.809**	
I've been turning to work or other activities to take my mind off things		-.304						**.683**

I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	-.378	.319	-.335	**.548**	
I've been trying to see it in a different light, to make it seem more positive					**-.886**
I've been looking for something good in what is happening	-.315				**-.816**

Extraction Method: Principal Component Analysis. Rotation Method: Oblimin with Kaiser Normalization.

ANOVA on the nine sub-scales identified by Factor Analysis

In order to explore whether the use of the intervention had any impact on the type of coping strategies used across the nine facets of coping identified through the Factor Analysis, a series of one-way repeated measures ANOVA were conducted to compare coping scores on each of these subscales at baseline time 1, time 2 and time 3. The analysis revealed that there was a statistically significant difference between the use of the intervention and the use of coping responses of denial, self -blaming and venting, and substance misuse over time. The intervention did not result in any significant change over time across the remaining coping strategies. As shown in Table 1.8 there was a significant effect of the use of the self-help coping leaflet on the use of the denial coping response, there was a gradual decrease in the use of this response over time from pre intervention baseline (time one) to post intervention time two and three..Wilks' Lambada = .61, *F* (2, 19) = 5.9, *p* = .01, multivariate partial eta squared = .38. There was also a significant effect of the use of the self-help coping leaflet on the self-blaming and venting coping response, there was a gradual decrease in the use of this coping response over time from pre intervention baseline (time one) to post intervention time two and three..Wilks' Lambada = .56, *F* (2, 19) = 7.3, *p* = .004, multivariate partial eta squared = .43. There was a significant effect of the use of the self-help coping leaflet on the use of the substance misuse coping response, there was a gradual decrease in the use of this response over time from pre intervention baseline (time one) to post intervention time two and three..Wilks' Lambada = .72, *F* (2, 19) = 3.5, *p* = .04, multivariate partial eta squared.

Table 1.8 ***Means and Standard Deviations on the measure of denial component at Time 1, Time 2 and Time 3.***

Coping Response	**Time 1** **(Pre intervention)**	**Time 2** **(Post intervention)**	**Time 3** **(Post intervention)**
Denial	Mean 2.7 (SD .95)	Mean 2.6 (SD 1.3)	Mean 2.3 (SD .92)
Self-blame & venting	Mean 14.7 (SD 3.3)	Mean 11.6 (SD 3.2)	Mean 11.4 (SD 3.1)
Substance Misuse	Mean 2.8 (SD 1.5)	Mean 2.3 (SD .74)	Mean 2.1 (SD .43)

Non-significant ANOVAS:

There was no significant effect of the use of the self-help coping leaflet on the use of the active coping and planning coping response- Wilks' Lambada = .93, *F* (2, 19) = .71, *p* = .50, multivariate partial eta squared = .07; on the use of the emotional and instrumental coping response- Wilks' Lambada = .85, *F* (2, 19) = 1.2, *p* = .31, multivariate partial eta squared = .11 and on the use of the humour coping response-Wilks' Lambada = .93, *F* (2, 19) = .70, *p* = .51, multivariate partial eta squared = .07.

There was also no significant effect of the use of the self-help coping leaflet on the use of the religion and acceptance coping response- Wilks' Lambada = .99, *F* (2, 19) = .07, *p* = .93, multivariate partial eta squared = .007 and on the use of the positive reframing coping response- Wilks' Lambada = .83, *F* (2, 19) = 1.8, *p* = .19, multivariate partial eta squared = .16.

The use of the self-help coping leaflet did not have a significant effect on the self distraction coping response-Wilks' Lambada = .81, *F* (2, 19) = 2.1, *p* = .14, multivariate partial eta squared = .19.

Summary: Impact of the intervention on coping responses

The analysis of the effect of the intervention on the nine coping subscales generated by the factorial analysis revealed that the use of the intervention significantly decreased the frequency of the use of denial, substance misuse, and self-blaming and venting coping responses. This finding is complementary to the findings of the main analysis which revealed that the use of the intervention decreased the frequency of the use of avoidance coping (similarly made up of denial, substance misuse, self blame, and behavioural disengagement including venting). The analysis revealed that the use of the intervention does not have a significant effect on other coping responses i.e. active coping and planning, emotional and instrumental support, humour, religion and acceptance, positive reframing and self-distraction. (Appendix D.4 reports the means and sig values of all the nine coping subscales as identified by the factor analysis).

Theoretical analysis exploring relationships between coping strategies and perceived stress in parents of children with developmental disabilities:

As discussed at length in Chapter two and three, existing evidence suggests a strong relationship between coping orientation and perceived stress in parents caring for their child with a developmental disability. The literature review in this thesis suggests that these parents utilise different coping strategies to deal with their stress based on their appraisal of the situation they are in. These coping techniques cannot be classified as inherently good or bad as they serve different adaptive functions in different situations (Folkman, 1982). With the aim to predict if coping orientations and parental distress make independent contributions to perceived stress an exploratory analysis exploring predictors of stress in parents of children with developmental disabilities was conducted at baseline (it was not possible explore predictions over time due to the small sample size with the follow-up data).

Correlations between variables

Firstly, relationships between the dependent variable perceived stress (as measured by the Perceived Stress Scale) and the predictor variables were explored using correlational analyses. Avoidance coping (as measured by the Brief COPE scale) was investigated using Pearson product-moment correlation coefficient at baseline. There was a strong positive correlation between the two variables, $r= .63$, $n= 88$, $p < .001$, with high levels of perceived stress associated with a high avoidance coping orientation. There was also a strong positive correlation between parental distress and avoidance coping, $r= .60$, $n= 88$, $p < .001$, with high levels of parental distress associated with a high avoidance coping orientation. Thus, the relationship between the use of avoidance coping techniques and stress is verified.

The relationship between perceived stress (as measured by the Perceived Stress Scale) and problem focussed coping (as measured by the Brief COPE scale) was also investigated using Pearson product-moment correlation coefficient at baseline. There was, however, only a small negative correlation $r= - .20$, $n= 88$, $p =.052$, (Cohen, 1988) established between perceived stress and problem focussed coping. There was also a medium negative correlation between problem focused coping and avoidance coping variables, $r= -.31$, $n= 88$, $p = .003$, with higher orientation towards problem focussed coping associated with a lower orientation towards avoidance coping.

The relationship between perceived stress, parental distress and the demographic variables was also investigated using Pearson product-moment correlation coefficient at baseline. There were however no significant relationships between these variables.

Analysis II: Theoretical predictors of stress

Standard Multiple regression analysis

After establishing the relationship between coping and perceived stress through the correlational analysis, a standard multiple regression was conducted at baseline to evaluate each independent variable (type of coping response and parental distress) in terms of its predictive power, unique variance over and above that offered by all other independent variables.

Assumptions were checked for multicollinearity, where tolerance values for the variables was between .58 and .92 these values are not less than .10,therefore did not violate the multicollinearity assumption. This was also supported by VIF values ranging between 1.08 to 1.72, which is well below the cut-off of 10. The inspection of the normal probability plot and scatterplot of the Regression Standardized Residual indicated that the residuals were roughly rectangularly distributed and there were no outliers in the data. The value for Cook's Distance was checked (.15) suggesting there was no undue influence of any case on the results of this model. All assumptions for outliers, normality, linearity, homeoscedasticity and independence of residuals were met before the analysis was conducted. The required sample size for this analysis using the formula by Tabachnick & Fidell (2013) (N> 50=8m) was 90, the sample analysed for this study is not exact, but close N=88.

A significant regression equation was found F(4,83)=22.4, p= .000, with an R^2 of .52. Table 1.9 summarizes the results. The results of the regression indicated that the parental distress significantly predicted perceived stress (β =.43, p≤.001) and avoidance coping made a unique and statistically significant contribution to the prediction of perceived stress (β =.35, p≤.001). Parental distress makes a unique contribution of 11% to the explanation of variance in perceived stress, followed by avoidance focused coping which makes a unique contribution of 7% to the explanation of variance in perceived stress. The other two variables of active emotion coping (β =.02, p=.71) and problem focused coping (β =.02, p=.77) did not make a significant unique contribution to the prediction of perceived stress. *Table 1.9 Summary of Standard Regression Analyses for Variables Predicting Perceived stress in parents of children with developmental disabilities (N=88)*

Variable	B	SE(B)	β	t	Sig.
Active coping	.03	.09	.02	.36	.71
Avoidance coping	.56	.16	.35	3.56	.001**
Problem coping	.03	.13	.02	.29	.77
Parenting distress	.31	.06	.43	4.53	.000***

*p ≤ 0.01; **p ≤ 0.001; ***p ≤ .000

Leaflet usage

In order to gauge the usage of the coping leaflet at Time two and Time three the frequencies of the process measures were analysed. These results are reported in a table (Appendix D.5). At Time two, 51.3 % of the participants used the coping leaflet more than twice a week in comparison to 38.2% at Time three. 72.2% of the participants at Time two used the coping techniques for more than 10 minutes each time they used the leaflet in comparison to 61.9% who used it for the same duration at Time 3.

Frequency of leaflet usage and stress:

An independent samples t-test was conducted at Time two, to compare the level of perceived stress in participants who used the leaflet just once a week (n=12) and participants who used the leaflet more than once a week (n=25). There was no significant difference in the levels of perceived stress for participants who used the leaflet once in a week (*M*= 22.08, *SD*=6.21) and participants who used it more than once a week (*M*= 20.20, *SD*=7.19; *t* (35) = 0.77, *p*= 0.44, two-tailed. The magnitude of the differences in the means (mean difference = 1.88, 95% *CI:* -3.03 to 6.80) was small (eta squared .04).

Free text comments

In addition to the process measure questions about the usage and efficacy of the coping leaflet, participants were asked about what they liked or disliked about the coping leaflet and their experience of using it. Of the 37 participants at Time two, 20 provided the additional qualitative comments. At Time three, six out of 21 participants provided these additional comments.

Qualitative content analysis: The comments and feedback provided by various participants at Time two and Time three were analysed with the aim of identifying any common concerns and experiences regarding the self-help coping leaflet.

Content of the leaflet

There was a mixed reaction of participants in terms of the techniques mentioned on the coping leaflet. Four of the 26 participants who provided feedback regarding the leaflet reported that they felt that the content of the leaflet (techniques) was rather simplistic and patronising.

It felt a little simplistic/patronising. If I could do all these things I would already have. (18, t2) .

Another participant also felt that the techniques they were asked to practice were patronising, the leaflet did not provide them with practical solutions or help as they expected it would, they said:

I'm very sorry but I found the techniques in the leaflet unhelpful and somewhat patronising. I would rather that some practical help with actual problems was available, as a way to reduce legitimate concerns that I have as a result of very poor service provision to my child. (20, t2)

One of the participants also mentioned that the techniques on the leaflet are too simplistic and may not be easy for people like her to follow due to their excessive time commitments towards their caring responsibilities:

Some of the strategies are particularly difficult for people with little or no support - you can't take time out as a single parent with no family or *social worker to rely on, my daughter doesn't give me peace to do things alone so I can't complete activities for me at home unless she is sleeping and even then I have chores and things that need to be done to get us through the next day/week. Seems a little too simplistic, and I'm actually someone in a happy marriage with family around us as well! (7, t2).*

Somewhat similarly another participant suggested that these techniques are not something they are unaware of but it is their busy caring schedule which does not give them time to practice suggestions such as these. They also indicated that the leaflet was rather a useful reminder of strategies but they found it hard to devote time due to their busy schedule:

I would like to have used it more but found it very difficult to get any time to look at it. None of the suggestions were ground breaking but I thought it was a good reminder of stratagems I could use. It is not that I don't know about them it is simply impossible to find the time or headspace to think about it. (2, t3).

In contrast to the above, there were other participants who revealed that the techniques mentioned on the leaflet had been useful and helpful for them and the techniques could be used on a day to day basis:

Just taking a second to think of one of the coping techniques helped. (1,t2)

Found it useful to use on a day to day basis. (10, t2)

Participants also revealed that based on the fact that the techniques are simple they were motivated to use them frequently and think about their situation in a different light:

I enjoy practising the things mentioned in the leaflet, they were simple and helped me to view things differently but I am not certain if this will be a long term thing. (15, t2)

Another participant remarked that the using the leaflet helped them to avoid building up on negative emotions and also perceiving their current situation with a more positive outlook:

I find that I am coping better and the situation is not always as bad as it first seemed. Before doing this, I had so much to do, I did not know where to start and left it all build up. Thank you very much for the leaflet, it has helped a lot. (06, t3)

It was also reported that the leaflet proved helpful to deal with stress and as the techniques became familiar with practice the user didn’t need to refer to the paper copy each time someone needs to refer to the coping techniques:

Quite a useful way of coping with my worries, it has proven helpful so far and

I know the techniques now so don't need to refer to it again and again. (04, t3)

One participant acknowledged that the information provided on the leaflet was useful but to practice the techniques on a continual basis would need motivation and effort from the user:

The coping leaflet contained useful information and I tried and practiced a few things. It will take time, effort and continuous motivation to be able to continue using the same over a length of time so that it becomes part of my day to day life. (11, t2)

Some of the participants who used the leaflet gave some suggestions with regards to improving the leaflet further in terms of making it more user friendly. Most of the participants who commented about the format preferred the paper based version of the leaflet.

Having a paper version to hand would have been a better way to go. (2, t2)

They suggested that the leaflet is easily accessible in the paper format and therefore it is easy for them to refer to it and use it often:

It is good to have it handy so I can access it anytime. I am getting use to using it often now (10, t2)

The coping leaflet is handy to have around to have a look at and remind yourself of different ways of coping (14, t2).

However, one of the participants suggested that they would prefer the leaflet in a phone friendly format for an easier access:

Would be good to have in a more phone friendly format. With daily reminders to take a look and try things. Print out wasn't practical and I don't always go into emails or pc every day. (1, t1)

Four of the participants also commented on the likelihood of the future usage of the leaflet. They acknowledged that their schedules make it very hard for them to follow the techniques on a regular basis:

I would like to have used it more but found it very difficult to get any time to look at it… It is not that I don't know about them it is simply impossible to find the time or headspace to think about it. (2, t2).

I would like to have more time to actually do the things on the leaflet. (6,t2).

Another participant commented that they enjoyed using the techniques mentioned on the leaflet as these were simple to practice and encouraged to look at the positive side of their situation but they were not sure if they would be using the leaflet on a long term basis.

I enjoy practising the things mentioned in the leaflet, they were simple and helped me to view things differently but I am not certain if this will be a long term thing. (15, t2)

I am getting use to using it often now (10, t2).

There were suggestions made for the further improvement of the leaflet and the users noted the points they did not particularly like about this intervention.

One of the user particularly commented upon the layout and design which they considered was not appropriate:

I didn't like the presentation - the font seemed too childish, the various different colours of text was unnecessary, and the clip art was poorly laid out and ineffective, not really needed at all. (7, t2).

A few participants commented on the nature of examples in the leaflet and suggested that using practical examples would have made it better for them, they suggested that the leaflet may be more reliable if there were some testimonials or case studies reflecting how these techniques have worked for people in a similar situation as theirs:

Would have liked some more practical examples, maybe some case studies or testimonials (anonymous). (3, t2).

Someone also suggested that they rather that the leaflet offered some practical help in terms of the problems they face in regards to the service provision to their child:

I would rather that some practical help with actual problems was available, as a way to reduce legitimate concerns that I have as a result of very poor service provision to my child. (20, t2).

There were two participants who mentioned that they were already making use of the techniques mentioned on the coping leaflet prior to receiving it.

Most of it was things I was already doing. (17, t2).

Many of the techniques I already use, such as taking time to myself, distraction and thinking of positives. (9, t2).

Overall, the results indicated that the leaflet may be of benefit for parents aiming to minimise stress in their day to day lives, most of the participants who chose to comment felt that the coping leaflet was a useful and helpful tool in helping them to deal with their stress. Some participants suggested that the techniques mentioned on the leaflet were not new to them as some of were already using certain techniques in the past or prior to receiving the leaflet to deal with their stress. This suggests that not all the techniques put together in the coping leaflet were new to the parents, it may hence be useful to be able to identify and offer coping techniques which are both novel and productive for this cohort. However, addressing this issue of novelty may not be as straightforward as there will always remain a case where some techniques are already known to some of the participants.

There were also differences in terms of the suggestions made by the participants in terms of the mode of delivery of the leaflet, the content and layout. One of the participants' commented that they were not impressed with the layout in terms of the font and clip art used on the leaflet. However, these changes were made to the leaflet on the basis of the first study where most participants indicated that the use of different colours would make it more visually appealing and easier to differentiate between techniques. As the leaflet was aimed at people with varied reading abilities the addition of pictures clues was considered useful for some people who struggle with reading content, this suggestion was also a part of the first trial of the coping leaflet and was implemented as considered useful. In the present study a suggestion was made in terms of adding case studies and testimonials for the leaflet users. This suggestion however, cannot be implemented in the leaflet itself as (1) being the first study of this nature no testimonials are available so far and, (2) adding these might considerably add to the content of the leaflet distracting the user from the main purpose it is designed for. For future use however, this additional information can be provided as a separate annex to the leaflet.

The analysis also revealed that some of the participants expected that the leaflet may offer some practical help in terms of their caring duties in addition to the coping techniques. The leaflet used in the present study aimed at helping parents to cope more effectively with their stress and hence relevant coping techniques were identified and put together. It was beyond the scope of this leaflet to offer any practical help or guidance for the parents in terms of providing care to the child or improving service provisions in any way whatsoever. However, the leaflet aimed to promote the use of effective coping strategies in parents which may ultimately have an effect on the care provided to the child.

The leaflet was perceived as simplistic and patronising by some of the participants, this feedback is of importance as it indicates that not all users were satisfied with the leaflet and on the contrary thought the content was patronising and not novel for someone in their situation. The final version of the leaflet was adapted in light of feedback gained from the first study conducted to assess its acceptability, the issue of it being simplistic and patronising was not identified in this study and therefore not recognised and addressed. However, the present study with a larger representative population indicated that this maybe a potential put off for some participants as the balance between the content being simplistic and overly simplified may not have been achieved. The decision to make the content of the leaflet simple and fairly easy to understand was based on the fact that the users may be of very varied intellectual abilities and it was intended that the leaflet contained simple yet relevant information which is easy for participants to read, comprehend and implement. Even though not intended, this may have resulted in an oversimplification of content leading to a few participants considering it as patronising.

Discussion

This chapter presents the results of this exploratory trial the aim of which was to assess the effectiveness of the self-help coping leaflet in terms of levels of stress, orientations towards coping and usage. The following section discusses critically the findings of this study, its implications in terms of theory, the impact of the intervention on the stress and coping orientations, the acceptability and usage of the intervention and the analysis of study dropouts. It then discusses the methodological limitations of the present study and future directions, which may inform similar research.

The impact of the intervention on stress and coping orientations

The coping leaflet designed for the use of parents in this study was guided by the principles of the Double ABCX model (McCubbin & Patterson, 1983) and the transactional model of stress and coping (Lazarus & Folkman, 1984). These models suggest that coping is essentially a process and should be thus measured over time as it may change due to the constant evaluation or appraisal of the relevance of the stressful situation. The intervention aimed to help the user of the intervention reappraise the stressful situation by practicing techniques which are active emotion focussed in nature. The results show that the intervention significantly reduced self-reported stress and as the participants made use of the leaflet they registered a reduction in their levels of perceived stress and parental distress. This reduction was relatively stable over time as there was no significance difference between the stress levels of participants at Time two and Time three. This suggests that using the coping techniques on the leaflet (as measured by the leaflet usage) aided in minimising stress from baseline to time two and the continuation of practice of these techniques helped to maintain these stress levels relatively.

In terms of the changes in the coping orientations, the results did not support the hypothesis that the use of the intervention will lead to a higher use of active emotion focussed coping techniques. Contrarily, the intervention did not have a significant impact on the active emotion dimension of coping. The mean scores of active emotion coping did not differ significantly at baseline or follow up. Lazarus & Folkman (1986) suggested that emotion focussed coping can be relatively stable over time as it is more influenced by person factors. In relation to the results of this study, this suggestion may be apt as there was no significant difference noted in the use of this particular coping style. In order to notice a significant change in active emotion coping it may have been ideal to make the intervention available for a much longer period of time and as Lazarus & Folkman (1998) recommend that there must be multiple assessments in order to examine changes in coping over time. Another factor which needs consideration whilst interpreting these findings is that whilst the stress and coping were measured at different time points there was no data gathered to recognise the momentary properties or changes in the stressor or stress encounter which may have had a bearing on the stress and coping responses of the participants (Folkman & Lazarus, 1985). The results however revealed that there was a significant reduction in the use of avoidance coping between base line and follow up. This finding in the results could be attributed to the fact the intervention actively promoted the use of active emotion coping. It encouraged participants to use techniques that initiate active emotion coping which are conversely related to avoidance coping. It can be argued that because participants were encouraged to use active emotion coping, it may have led to a decrease in the frequency of using avoidance coping causing a negative relationship between these two forms of coping. Therefore, participants who used the intervention minimised their use of avoidance coping techniques. This decline in the use of avoidance coping and lower stress can be explained by literature which suggests that there is a positive correlation between avoidance focussed coping and long term stress (Blalock, & Joiner, 2000; Billings et al., 2000; Holahan, Moos, Holahan, Brennan, & Schutte, 2005; Sherbourne et al., 1995).

Analysis of study dropout rates:

Longitudinal studies usually suffer from attrition, where, participants may drop out of the study earlier than scheduled, for reasons outside the control of the researcher

(Verbeke, Lesaffre, & Spiessens, 2001). The present study also had a high attrition rate. There was a substantial difference between participant numbers at baseline and subsequently (time two and time three), this has caused considerable limitations in terms of data analysis and generalizability of the findings. This nonresponse appeared at all the three stages of the present study (i) initial non-response at recruitment, where anticipated number of participants was not obtained after invitation to participate in the study, and, (ii) at follow up times where non-response occurred post intervention. From baseline to Time two the participation rate for the study was 42.05 percent at time two, which is comparable with previous research in disability studies (e.g. Hudson et al., 2003; Kazdin, 2005; Roberts, Mazzucchelli, Studman& Sanders, 2006). However, the participation rate from baseline to Time three was 23.86 percent which is lower than most studies. Nevertheless, if the participation rate between Time two and Time three is analysed there is a high retention for participants indicating that the that parents who chose to remain in the study after Time two had a higher commitment towards completing the study than those who chose to complete it at only Time one or Time two. In terms of research participation in longitudinal studies, it is likely that there are significant differences in non-volunteers for the initial phase of the research in comparison to those who initially participate but drop out in a follow-up phase; for example, the former might be totally disinterested whereas the latter might be expecting some form of reward (lower stress in this study) with the participation (Dollinger & Leong, 1993). When compared on the average stress score on measures of perceived stress and parental distress, participants who only completed the baseline assessment had a lower score in comparison to stress scores of participants who remained and continued with the study at Time two and Time three. It may be therefore possible to conclude that the participants who had a higher stress score chose to remain in the study at follow up with the aim of reducing their stress, suggesting a continuous endeavour on the part of a parent in dealing with this stress. There were no significant differences noted in any of the other demographic variables measured between the participants suggesting the sample was a homogeneous one.

Acceptability use of coping techniques

The participants had a varied preference in terms of the coping techniques they most frequently used from the leaflet. At Time two when the participants were first asked to use the intervention, the results indicated that the most used technique was taking time out, followed by expressive writing and distracting from worries. Taking time out encouraged the participants to take some time off their parenting responsibilities to deal more effectively with day to day stress (Taanila, Syrjälä, Kokkonen & Järvelin; 2001). The results of the present study revealed that this technique was the most frequently used amongst the four mentioned on the coping leaflet at both Time two and Time three. It can be argued that taking time out is a technique that may give the participant a feeling of self-efficacy or some sense of control over their time and the results of practicing this technique can be more or less experienced immediately.

Benefit finding was another popular technique with the participants at Time three, this technique of coping encourages positive reappraisal and helps an individual to sustain coping efforts in stressful situations (Folkman, 2008). On the other hand, expressive writing was not a preferential technique amongst the participants after the first week. Distracting from worries remained a preferential technique amongst the participants both at Time two and Time three, literature suggests that the use of distraction coping by parents of children with disabilities relates to less negative moods (Lyons, Leon, Phelps & Dunleavy, 2010; Pottie & Ingram, 2008) and therefore this remains a popular choice for parents. The results indicated that there is variation in terms of what techniques the participants preferred, this may be due to personal choices which may be affected by factors such as previous experiences, expectations and beliefs and personality types.

In terms of time spent by the participants on practicing techniques mentioned on the leaflet, at both time points most participants used it up to twice a week with an average use for between 10-20 minutes each practicing a technique. There was no time specified allocated to practice the techniques and it was up to the participant to decide which technique they preferred to use and for how long. The participants were given this option so they may be able to decide what works best for them and how long they can last whilst practicing the techniques offered to them. This decision was made to ensure that they do not feel unduly obliged to spend a specified portion of their busy caring schedule toward a research study but rather feel at ease and practice when they are able to. In terms of the future usage of the leaflet, the analysis of the free text comments revealed that whilst some participants were confident that they would continue the use the techniques on a long-term basis a few were unsure about whether or not they would use the leaflet in the future. As this study was the last one conducted for this thesis detailed reasons from the participants contributing to their decisions of whether or not they will continue to use the techniques could not be explored.

Limitations

In discussing the findings and implications of the present study, it is important to acknowledge its limitations too. A key limitation of the present study is that the intervention was tested on just one group at different time points; the study did not have a control group to match its findings against. Shadish, Cook, & Campbell, (2002), suggest that the best design for detecting causal effects is the randomised control trial, so that an intervention effect can be estimated by post-treatment or follow-up outcomes for the intervention group with control-group outcomes. They further propose that as distribution of all potentially confounding factors is balanced across experimental conditions by this design (randomised control trial) differences in outcome in different groups can hence be attributed to different interventions or comparators. For the present study this lack of a comparison group may result in potential for confounding variables (Grimes, & Schulz, 2002) affecting the overall findings of this research as these confounding factors may mask an actual association or, more commonly, falsely demonstrate an apparent association between the intervention and outcome when no real association between them exists (Skelly, Dettori & Brodt, 2012). Together, these considerations in design may restrict the generalizability of results and the attribution of causality to the intervention. Although this does not preclude causal inference from this within group study, it limits the generalizability considerably, for these results to be generalized a larger and preferably, a randomized controlled trial needs to be conducted.

The results of this study suggested that practicing the coping techniques on the leaflet (as measured by the leaflet usage) aided in minimising stress from baseline to time two and the continuation of practice of these techniques helped to maintain these stress levels relatively. This finding needs to be interpreted with caution as there could be a variety of interacting factors along with the key intervention components which may have contributed to these scores in addition to the use of the leaflet. For example, certain traits such as dispositional optimism may have a better response to an intervention and research shows that dispositional attributes impact on coping outcomes (Lancastle, & Boivin, 2005). Research supports dispositional optimism as a resilience factor for parents of children with disabilities. Kayfitz, Gragg, and Orr (2010) explored the impact that positive experiences had on mothers and fathers of children with autism, and found that positive experience scores were significantly negatively correlated with parental distress. They argue that parents who were able to view the contributions of their child more positively experienced relief from the parenting stress associated with caring for their child. The authors speculate that having a more positive approach to viewing their child allows parents to pay less attention to the child's limitations and, in turn, potentially pay less attention to their limitations as parents, which offers protection against a negative sense of well-being. Studies have shown associations between optimism and the use of coping strategies that aid recovery (Folkman & Lazarus, 1988). Therefore, personality variables such as these might have played a key role in the findings of this study. Other factors contributing to these results could also be the personality traits, which play a role in volunteering or self-selection. Studies indicate that volunteers are more agreeable and open to experience in comparison to the non-volunteers (Dollinger & Leong, 1993). Conscientiousness has also been associated with research participation more generally, it is related to sense of duty (Costa and McCrae, 1992), a trait that might explain why individuals consent to devote their time and effort to serve as a research participant for little or no external reward. Furthermore, high extraversion has been associated with volunteering (Carlo et al., 2005), as volunteering may often require some form of social interaction. This volunteer bias may have led to motivated individuals to partake in this research study thereby having an influence over the overall results as these self-selected individuals are more likely to be led by the belief that the intervention which was aimed for them will yield results in their favour (Floyd, & Gallagher, 1997; Lonnqvist et al., 2007; Sloper & Turner, 1992). In terms of participants in the present study it is important to consider that participants for this study were volunteers who chose to be a part of this study trial. It must be stressed that there is no comparative data to show the differences between the participants and for parents who decided not to take part in this study. The participants who used the intervention did so out of their free will, indicating that they were motivated enough to participate in a study, remain in it for about three weeks and use the intervention. Their motivation behind being a participant maybe their belief in terms of using the intervention and thereby drawing benefits in terms of reducing their stress levels. In future studies of this nature, identifying personality types and motivations to partake in intervention studies can be duly explored.

It is also to be acknowledged that coping behaviours might be a short-term mechanism which may be influenced by a number of personal, social and contextual factors, in the present study no momentary or situational properties of the participant’s life were noted or measured in any way. Folkman & Lazarus (1985) argue that to be able to examine a stressful encounter without the recognition of the fact that its momentary properties may change can be misleading. They further suggest that an implication of this may be that one of the most important features of human adaptation, the way people change troubled person-environment relationships through coping, is ignored if these momentary properties are not identified. It should be borne in mind when considering the results of the present study that for practical reasons such as time pressures, participant burden, it was not possible to measure all these factors. Therefore, the extent to which these momentary properties may have influenced the associations in the present study are not known. It should hence be noted that in addition to the information on momentary or situational factors further research is also warranted on the long-term effects of coping styles and their stability across life situations (Dunn et al., 2001).

Another limiting factor in the present research was the sample size, which curtailed methods of analyses that could have been employed to examine the data further. There was a major dropout rate in the study at Time two, with only 42 % of the total participants continuing with the study. On reflection this attrition could be owed to a number of factors such owing to life circumstances which in this case may be due to care giving demands or other personal factors (Kazdin, 2005). Childhood disability research studies support this as attrition rates (e.g. Bischoff & Sprenkle, 1993; Heinrichs, Bertram, Kuschel, & Hahlweg,2005; Ingoldsby, 2010; Kazdin, 1990). Another plausible reason for the drop out at the follow up times (time two and time three) could potentially be the use of the same measures or questionnaires repeated in a brief period, this repetitive nature of tasks and a lack of novelty might cause a lack in interest in participants thereby limiting the responses at follow up. An additional limitation in terms of the sample characteristics in the present study is that only five males consented to take part, resulting in a gender bias as the number of female participants in the present study was clearly high in comparison to male counterparts. This however, is a common issue in childhood disability studies where mothers are always a dominant sample (Dabrowska, & Pisula,2010; Flippin, & Crais, 2011; Hastings, 2003). According to Hayes, & Watson, (2013), this gender bias can be attributed to the fact that mothers are the primary caregivers, are most likely to be off work to look after the child and also likely to participate in research studies as they are best placed to answer questions regarding their child or the effect of the disability on the family. Findings from the present study cannot be generalized to fathers as their appraisals, stress and ways of coping may be relatively different to that of the mothers. Further probing the participant pool of the study, the characteristics of the sample may limit the extent to which the findings of this research may be generalised. Participants in this research were individuals who could communicate in the mode of English and most of them were predominately educated and technology literate sample of mothers, thus limiting the generalization of study findings to lesser-educated populations, as well as to fathers and other caregivers. In relation to the measures used in the present study, all measures had a good reliability score other than one of the sub scales in the coping measure (Brief Cope, Carver, 1997), which was lower than is generally accepted to indicate satisfactory scale reliability. Many studies in the past have used this scale and obtained similar reliability values (e.g. Benson, 2010; Hastings et al., 2005; Seymour, Wood, Giallo, & Jellett, 2013; Yusoff, Low, & Yip,2010), however, the results obtained should be interpreted cautiously in the light of the low Cronbach's alpha for this scale. It is also important to mention that the measures used in the present study were based entirely on self-report and thus there is a possibility that some of the associations noted were inflated due to common-method variance (Lindell & Whitney, 2001; Schaller, Patil & Malhotra, 2015). To overcome this, there was a time gap between the data collection at all three time points of the study, however, the measures and format was the same for all the studies and hence the results require a careful interpretation.

Conclusion

Results of this exploratory study indicate that the self-help coping intervention, was considered to be an acceptable and feasible intervention for a majority of participants in the present research. Even though not intended, a small minority of the participants reported that they felt that the intervention was “patronizing”, for this effect, the content of the intervention needs to be assessed again possibly by a much larger number of parents with a varied demographic composition. This may allow for a varied response towards the content of the leaflet, for example, parents who are self-efficacious may find the intervention patronizing as opposed to those are less confident of their abilities. A large sample in a new feasibility study may ensure that this issue can be identified and addressed accordingly.

It was expected that the use of the intervention would lead to a higher use of active emotion coping which will then lead to lower stress in parents using the intervention. The results indicated a decline in the participants stress scores which is reassuring, however, there was no significant rise noted in the use of active emotion coping. As discussed previously, this may mean that the active emotion coping techniques did not work directly to affect the stress scores but indirectly, as practicing these techniquesreduced the frequency with which the participants used avoidance coping. The frequent use of avoidance coping can exacerbate stress if the stressor is long term or chronic (in this case the chronic disability) and parents using avoidance coping may worsen their stress with time. The results of this study indicate that a decrease in the use of avoidance coping led to a decrease in overall stress scores of the participants. These results are promising and warrant further investigation with a larger number of participants in perhaps a randomized controlled trial to establish the extent to which it can be a beneficial addition to support parents of children with developmental disabilities. To overcome the limitations of the present study, sampling strategies for the RCT may include robust criteria for recruitment of a more diverse group of participants in terms of age, educational background, and gender in particular. It will also be ideal to collect data on personality variables in this trial to be able to assess the role of personality in the acceptability of the current intervention.

CHAPTER 8

General Discussion

The aim of this thesis was to understand the parents perception of their stress and efficacy in coping associated with caring for a child with a developmental disability. The thesis also aimed to develop a brief self-help coping intervention for these parents and assess its feasibility and acceptability. Finally, it aimed to evaluate the impact of use the intervention on the stress and coping behaviours of parents caring for their children with developmental disabilities. Three studies were carried out to meet these aims and provided important insight into the experience of parenting a child with a developmental disability and on the potential effectiveness and acceptability of a brief self-help coping intervention. Overall, the findings from the thesis support this existing evidence that parenting a child with developmental disability can be very stressful (e.g. (Estes et al., 2009; Beck, Daley, Hastings, & Stevenson, 2004; Grosse et al., 2009; Meppelder, Hodes, Kef, & Schuengel, 2015). The findings also revealed that the use of the self-help coping intervention over time significantly helped the parents' in minimising their levels of stress. It is currently unclear however, which components of the intervention were most effective in minimising stress. It is not known at this point whether it was only the emotion active coping techniques or a multitude of other factors and coping mechanisms that influenced the levels of stress amongst the users of this intervention.

The detailed findings and methodological considerations of each individual study have been presented and critically discussed within the discussion chapter of each empirical chapter. This final chapter attempts to draw together the key messages from each chapter within the thesis, critically discussing the extent to which these studies collectively add to the existing evidence base and producing a set of recommendations for both the practical implications of this research for families with children with developmental disabilities and for this academic field in relation to future research.

Summary of findings:

Aligned with previous research, the first study of this thesis revealed that for parents caring for a child with a disability balancing the regime of complex treatment schedules, a very busy family and work life, lack of respite, social or leisure activities and unexpected or sudden changes in the child's health cause considerable stress (Knussen & Sloper, 1992; Barlow, Powell & Gilchrist, 2005). However, many parents who participated in this study also highlighted the positive contributions of their child in their lives, pointing to the positive adaptation that these parents make while dealing with the long-term stress of their child's disability. This finding from the present study is also consistent with prior research which suggests that caring for a child with a developmental disability can increase the family members' tolerance, compassion, awareness of their inner strength, enhance family cohesion and broaden their perceptions and thoughts (e.g. Kausar, Jevne & Sobsey 2003; Reichman, Corman & Noonan, 2008). This gradual positive adaptation of the parents' appraisal of their child's disability enhances their coping and highlights the ever-changing facet of the stress and coping process.

The second study of this thesis aimed to determine the appropriateness and the potential effectiveness of the coping intervention designed for parents caring for a child with a developmental disability. In accordance with the MRC guidelines, the self-help coping intervention was adapted and developed to gain a better understanding of the likely process and effects of coping in parents caring for children with developmental disabilities (Craig et al, 2008; MRC, 2000, 2008). This coping intervention was adapted for these parents with the aim that it may be (1) theoretically derived, (2) simple enough for parents to use by themselves, (3) could be used by parents whenever and wherever they felt the need, (4) cost-effective enough to be made freely available, and (5) was generic enough to be used by parents caring for children with different diagnoses or severity of symptoms.

In the field of childhood disability, such an intervention is novel and may prove highly effective where there are limited opportunities for parents to engage in practitioner-based interventions for pragmatic or economic reasons. The results of the pilot feasibility study suggested that the provision of a self-help coping leaflet may be an appropriate and adequate intervention for parents to mediate their levels of day to day parenting stress by promoting effective coping techniques. The feedback obtained from them on the appropriateness of the self-help coping leaflet suggested that this intervention may be an efficacious tool in mediating levels of distress and enhancing coping effectiveness amongst parents. The participants also shared their views on how to further improve the existing coping leaflet. However, there were various methodological limitations such as volunteer bias, gender disparity and the researcher-participant relationship in the study which make the generalizability of the results rather limited (Costigan & Cox, 2001; McCambridge, Witton, & Elbourne, 2014). For example, men were under-represented in this study and this issue of an all-female participation is of importance, the risk it poses, is that of developing an intervention that may not be acceptable to men as their views have not been considered during the development and assessment of this intervention. The sample size in this study was small; therefore, generalizations may be limited.

The self-help coping intervention in this thesis was based upon the transactional model of stress and coping (Lazarus & Folkman, 1984; Folkman &

Lazarus, 1988; Lazarus, 1991) and involved the provision of a simple self-help coping leaflet encouraging participants to use active emotion coping techniques to help them to minimise stress and promote a sense of well-being. Theoretical and empirical evidence suggests that the use of active emotion coping techniques can be an effective strategy for dealing with stressors when few problem-focused strategies are available, such as in the case of receiving a chronic diagnosis. The final study of this thesis revealed that the coping intervention may be of benefit for parents aiming to minimise stress in their day to day lives by coping more effectively.

The combined findings of studies discussed in Chapters Six (Study two) and Seven (Study three) specifically investigated the effectiveness of the coping leaflet in reducing stress in parents caring for their child with a developmental disability. Study Two was an exploratory study which provided valuable information about the potential acceptability of the intervention. The qualitative data obtained from this study were used to further develop the intervention and aided the design of the questionnaire for Study Three. Study Three was an exploratory trial of the effectiveness of the self-help coping intervention and allowed the impact of the intervention on key psychological outcomes to be investigated. Additionally, free-text comments on the questionnaires relating to the use of the coping leaflet were analysed. This mixed-methods approach enabled a detailed exploration of the salient issues surrounding the use and effectiveness of the coping leaflet.

The results revealed that the intervention worked over time and as the participants made use of the leaflet they registered a reduction in their levels of perceived stress and parental distress. This reduction was also recorded as relatively stable over time. The use of the leaflet did not have a significant impact on the use of active emotion coping as hypothesised, but had a significant impact on avoidance coping. This could be attributed to theory that suggests that emotion focussed coping can be relatively stable over time and therefore to notice any change the intervention needs to be available for a much longer period of time and outcomes assessed over a longer time scale (Lazarus & Folkman, 1986). Though not hypothesised in this study, the finding that avoidance coping significantly decreased over time with the use of the intervention is an interesting and promising find as the use of avoidance coping has been likened with stress in parents dealing with a chronic stressor such as the disability of their child (Glidden, Billings & Jobe 2006; Hastings et al., 2005).

In terms of the content of the intervention, most of the participants in this research study indicated their preference of the leaflet whilst there were some who questioned the content in terms of its simplicity and as being patronising. These findings and implications have been discussed at length in Chapter Seven and indicate that there may be a need to revaluate the content of the leaflet and reassess its acceptability with a varied demographic population.

This thesis aimed to explore the use of the intervention and its effect on stress and coping, however, it needs to be acknowledged here that it is very difficult to capture these constructs in their entity thereby limiting the generalizability of these findings. It was acknowledged at an early stage of the thesis that the academic discussions related to the best way of conceptualising coping are complex and often difficult to test empirically. Reviewers of the coping literature often conclude that the transactional nature of coping is not captured to fully illustrate the dynamic, mutually reciprocal nature of appraisal and coping outcomes (Folkman, 2010). For example, even though several principles have been derived from coping research there is not much unanimity to measure the construct of coping as there have been several different models and hypotheses about the structure of coping (e.g. Endler & Parker, 1990; Lazarus & Folkman, 1984; Miller, 1994; Scheir et al., 1986; Skinner, Edge & Sherwood, 2003). The transactional model of stress and coping (Lazarus & Folkman, 1984) used as the theoretical framework in this thesis highlights the distinction between problem-focused and emotion-focused coping; two divisions which have served an important heuristic purpose in stress research. This model also highlights that these divisions cannot be classified as adaptive or maladaptive and that an individual’s appraisal of their situation is the key force behind choosing either of these coping techniques. The findings from the qualitative study (Study One) in this research similarly reveal that coping can be very subjective and each individual may appraise their situation uniquely and respond to it accordingly. Findings from this thesis suggest that even though the transactional model provides a simple division of the coping responses, it is an appropriate framework to use as it helps to understand the process of stress and the key role of coping in understanding the appraisal and adaptive processes involved in dealing with a stressor. Folkman et al. (1986) argue that the coping process and strategies selected are not inherently good or bad and therefore drawing a conclusion about which form of coping is better than the other is rather a difficult question to answer. Nonetheless, it is important for individuals to know which of these strategies is more effective in minimising their stress experience and differentiate it from the ones which yield a rather limited outcome.

However, some authors argue that the division of coping responses into problem and emotion focused oversimplifies how people deal with adversity (Carver, Schneier, & Weintraub, 1989; Lazarus, 1996; Skinner, Edge, Altman, & Sherwood, 2003). For example, certain coping techniques such as social support, fail to fit clearly into either the problem- and emotion-focused coping category. Notwithstanding, this can be addressed by choosing appropriate measures which can identify lower order coping mechanisms within these broad divisions. For this purpose, the present study divided coping mechanisms into three broad categories comprising that of active emotion, problem and avoidance focused coping techniques. Another theoretical model which provided a framework to this study was the Double ABCX model of family stress developed by McCubbin & Patterson (1983). This model was particularly relevant to this study as it is embedded into identifying how different families approach and deal with having a child diagnosed with developmental disability as it aims to explain how some families are able to cope with this situation rather resiliently whilst others become too subjugated. The multivariate approach of this model was relevant in examining how coping can lead to eliminate or avoid the stressor; to manage the stressful situation; to maintain the family integrity; and, to develop resources to manage the situation. The findings of this thesis suggested that both the transactional and Double ABCX models are parsimonious and explain the structure of coping clearly in relevance to the research aims. However, there are other influential models of coping which could have added to the overall quality of this study. One of these is the four-dimensional higher order structure model consisting of problem focused, distraction, avoidant and support strategies (Carver, Schier, & Weintraub, 1989). This model can add to the existing findings by exploring additional dimensions of coping that are especially useful in dealing with long term stressors such as a child's disability.

Limitations

There are clearly a number of important limitations to the overall findings of the thesis, however, these do not invalidate the results but limit the generalizability of these research findings.

A major drawback in the present research is the unequal representation of gender; most of the participants in this research were females (mothers) with a child with a developmental disability. The participation of fathers in this research is sadly negligible, despite the fact that that fathers are equally if not more stressed than the mothers of children with developmental disabilities.Based on their gender, the mother and father of a child with a developmental disability may have different appraisals of their child's diagnosis, and these different appraisals may affect both parents differently (Johnson, Frenn, Feetham, & Simpson, 2011; Smith, et al., 2010). This different perceptions of stress and coping cannot be addressed by research effectively if fathers do not participate in studies in more or less equal numbers to mothers (Johnson & Simpson, 2013). Men were not excluded during recruitment in any of the studies conducted as a part of this research and were given an equal opportunity to participate however none were recruited for the first two studies and only five chose to take part in the third and final study. A potential reason for this could be that most of the recruitment was done through advertising via support groups, charities and help centres, chances are that it is more mothers than fathers who frequent these groups or centres due to pragmatic reasons such as mothers being the primary care taker of the child (Smith et al., 2010), fathers unavailability due to work commitments (Johnson & Simpson, 2013) and a general tendency of fathers to be more introvert about their feelings of stress. For future studies, it will be sensible to consider fathers at the study design stage, as there are particular informational, financial, social, and psychological barriers that may preclude their participation (Macfayden, Swallow, Santacrocre & Lambert, 2011). Research also reveals that fathers may not appreciate that their views are valued, and may assume that the mothers' opinions may be more relevant (Macfayden, Swallow, Santacrocre & Lambert, 2011), particularly if the research focuses on the impact of their children's health conditions as in this study. For the purpose of future studies, the importance of the father's role needs to be highlighted at the study design stage so men may be reassured about the importance of their input in a research study. The limitation of this gender bias in the present study has led to implications, for example, the intervention in the present study was developed after views and feedback was taken from participating mothers in the feasibility study (study two) and all adaptations on the leaflet were made in accordance with this female exclusive feedback, as there was no male representation. These factors thus limit the intervention's acceptability in terms of being generalizable to fathers or other male members in the family caring for a child with a developmental disability.

Another key limitation of the present research is the lack of a longer term follow up data which could confirm the efficacy of the self-help coping leaflet, although this decision to collect quantitative data in nearly three weeks was based upon pragmatic reasons, future research should address this limitation by ensuring long term follow ups. As coping behaviour might be a short-term mechanism dependent upon a number of situational factors, further research is warranted on the long-term efficacy of coping styles. For the present research and to measure the effectiveness of the self-help coping leaflet, there is a need to determine whether the improvements in the parents' stress scores are maintained over time and whether their coping orientations change over time by making use of the self-help coping leaflet. A lack of longer-term follow up data in intervention studies such as this has to be acknowledged as a drawback in projecting the efficacy of the intervention.

The quantitative study in this thesis relied on the same measures and questionnaires to collect data across three different time points from the same study participants. This is another potential limitation of this study as the use of single retrospective measures is not considered appropriate to assess the dynamic and contextual process of coping over time (Pottie & Ingram, 2008). Many authors have criticised single retrospective coping measures for their susceptibility to recall biases and lack of clinical utility (Coyne & Racioppo, 2000; Smith, Leffingwell, & Ptacek, 1999). Pottie & Ingram (2008) suggest an alternative approach for the future study of stress and coping processes for parents and families. They suggest using a daily process design (Laurenceau & Bolger, 2005) which allows for the sampling of numerous coping responses and the stressful events and contexts that evoked them, while also reducing recall biases, by measuring coping and outcomes the day they occur. Future studies can thus use such varied measures to gain this information.

Another limitation of the overall findings in this thesis is the lack of data in relation to the situational or contextual properties and personality or disposition constructs. In terms of future studies aiming to understand this rather complex process, it is prudent to suggest that the adaptive qualities of the coping effort in parents caring for a child with a disability should be evaluated within the context of the specific situation in which it occurred. In terms of coping with the stress of parenting duties, certain coping processes may be successful within one context and not in another. This maybe be dependent on a number of factors such as the parent's appraisal of the situation, its relevance in the parent's life, their personality and disposition. A number of constructs have been introduced in the coping literature to explain the capacity of some individuals to maintain a positive outlook during negative life circumstances. Optimism (Seligman, 1991;, Carver & Scheier, 1991, 2001), sense of coherence (Antonovsky, 1988, 1993), hope (Snyder, 2000) and hardiness (Maddi & Kobassa, 1991) all refer to traits that are correlated with better coping under stress. There are a host of situational and personality variables that need to be measured in order to get affirmative answers to questions pertaining to coping choices and effectiveness. Folkman & Moskowitz (2000), suggest that factors such as these limit the findings of studies and therefore need to be addressed by identifying individual difference variables such as gender, personality factors; environmental variables such as interpersonal, social and cultural support; stressor characteristics such as behaviour problems or severity of diagnosis; emotion processing such as identifying specific emotion receiving attention, with attention to both positive and negative emotions.

For the findings of the present study to be more valid it would have been important to consider that every parent may bring a history of experiences of coping to any new situation, and this may affect the initial appraisal of an event as well as the choice of coping strategy. For example, parents' previous experiences of a disabling condition have been found to moderate parents' reactions towards the diagnosis (Fortier & Wanlass, 1984; Koch-Hattem, 1987). For future studies aiming to explore stress and coping in parents of children with developmental disabilities, it will be useful to research the effects of prior coping experiences (Farran et al., 1986) and how they influence the effectiveness or choice of future coping strategies.

Conclusion

Overall, the findings of this thesis confirm previous findings that being the primary care giver of a child diagnosed with a developmental disability can cause high levels of stress, although there are clear individual differences in how people experience and manage this stress. This thesis has shown that the individual differences reported through these experiences can be explained by the role of appraisals and coping offered through models of stress and coping (Lazarus & Folkman, 1984; McCubbin & Patterson, 1983). In addition to this thesis adding important insight into the ways in which parents manage this chornic stress and the many daily challenges associated with this role; the overall findings suggests that brief self-help coping interventions can be effective in helping parents to develop coping strategies to manage their stress. Whilst the active components of the intervention have yet to be fully identified, the coping leaflet appears to be a promising and effective intervention for parents who are likely to benefit from enhanced psychological support. There is also a need to identify more effective strategies to improve recruitment (particularly for male carers) and reduce attrition across such studies.

Whilst fully recognising the need to confirm these findings in a fully powered randomised controlled trial, information gained from the initial feasibility and acceptability research presented in this thesis suggest that within the context of parenting children with developmental disabilities, the “self-help” easily accessible nature of the coping leaflet may offer a low-cost but potentially effective coping intervention which could be integrated into the existing services available to these parents with minimal disruption. Future studies may also aim to develop web-based interventions such as in the forms of apps (online applications) which are almost always and easily accessible and may enhance psychological support to augment parental coping.

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Appendix A.1

SWANSEA METROPOLITAN UNIVERSITY
PRIFYSGOL FETROPOLITAN ABERTAWE

Study Information Sheet: Part One: Interview

"An analysis of the challenges and stressors experienced by the parents of children with neurodevelopmental conditions at different transitional stages".

You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being done and what it will involve.

Please take the time to read the following information carefully and discuss it with others if you wish. Part 1 tells you the purpose of the study and what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study.

If there is anything that is not clear or if you would like more information please contact Payal Sood on 01792 481000 (extn: 2161) or psood.128328@students.smu.ac.uk. Please take time to decide whether or not you wish to take part. Thank you for reading this.

Part One

What is the purpose of the study?

- The aim of the study is to identify the key problems and stress experienced by parents at various transitional stages of their child's development and to recommend ways of making transition periods easier to cope with. In total we hope to have around 15 volunteers taking part in the interviews for the first phase of the study, who would be parents of children with neurological conditions.

Do I have to take part?

- Taking part in this part of the study is voluntary and it is up to you to decide whether to continue taking part.
- If you decide to take part you are still free to withdraw at any time and without giving a reason.
- If you choose take part in this interview it does not mean you have to take part in the next part of the study: this is up to you.

What will happen to me if I take part?

- Once you have returned your completed consent form, you will be contacted by the researcher to confirm the arrangement for the interview.
- The researcher would arrange a suitable time and venue for the interview.
- The interview will last for about 40 minutes.
- With your consent, the interview will be tape-recorded in order to transcribe and anonymise the transcript for analysis.

What do I have to do?

- If you decide to take part you will need to sign and return the consent form. The researcher will then contact you with further arrangements for the discussion group.
- During the interview, the researcher will ask you about the stress you experience in parenting a child with neurological condition.
- You do not have to answer every question and are free to withdraw at any time.

What are the possible benefits of taking part?

- There will be no direct clinical benefit to you from taking part in this study. Your experiences are important to us and may enable us to identify and develop ways of helping parents of children with neurological conditions to cope with their stress at certain transitional stages.

What are the possible disadvantages and risks of taking part?

- It is highly unlikely that anything should go wrong. However, if taking part in this study does raise concerns, you are free to withdraw from the study and/or call the Cerebra helpline on 0800 328 1159.

What will happen if I don't want to carry on or if there is a problem?

- If you decide to take part you are still free to withdraw at any time and without giving a reason
- Any complaint about the way you have been dealt with during the study will be addressed.

Will my taking part in this study be kept confidential?

- All information will remain strictly confidential. The details are included in Part2.

This completes Part 1 of the information sheet. If the information in Part 1 has interested you and you are considering taking part, please continue to read the following information in Part 2 before making any decision.

Part 2

What if there is a problem?

- If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions on 01792 481000 (2161).

Will my taking part in this study be kept confidential?

- Throughout the research all information will remain confidential and you will only be referred to by your first name.

- With your consent we may like to use the words you have used in your interview in the presentation of the research. During the interview you will only be identified by your first name. With your consent, this discussion will be recorded and transcribed. Only the researchers will have access to the recordings, which will be kept in a secure place and will be destroyed at the end of the research, one year after publication.

- Any words used will be anonymised through the use of pseudonyms and modification of any personally identifiable information (names, places etc). Any published data will be anonymised in accordance with the Data Protection Act 1998.

What will happen to the results of this part of the research study?

- The results of the wider study will be disseminated through Cerebra. The results will also be presented at conferences and published in an academic journal.

Who is organising and funding the research?

- The study is being run by the School of Psychology & Counselling at Swansea Metropolitan University and has been funded by Cerebra the Charity for children and young people with neurological conditions as part of its Research Scheme.

- The study is being supervised by Prof. Ann Edworthy, a practicing Chartered Psychologist and Dr Ceri Phelps, a practicing Health Psychologist registered by the Health Professions Council (HPC).

Who has reviewed the study?

- This study has been approved by Swansea Metropolitan University's School of Psychology & Counselling Research Ethics Committee (SREC), bound by the ethical guidelines of the British Psychological Society.

For more information about the study
please contact Payal Sood:

Tel: 01792 481000 (2161)

Email: psood.128328@students.smu.ac.uk

School of Psychology & Counselling

Swansea Metropolitan University

Townhill Campus

Townhill

Swansea

SA2 0UT

Appendix A.2 Consent Form Phase I: Interview

"An analysis of the challenges and stressors experienced by the parents of children with neurodevelopmental conditions at different transitional stages".

Name of Researcher: Payal Sood

Please initial each box

1. I confirm that I have read and understand the information sheet dated dd/mm/yy (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

3. I agree to the interview being tape-recorded, and agree that any words that I may use during the interview can be used anonymously, in the presentation of the research. ☐

4. I agree to take part in the interview. ☐

Name of Participant **Date** **Signature**

Contact Details: (Please write clearly)

Full Name:______________________________________

Contact Email: __________________________________

Contact Tel Number: _____________________________ Preferred time for contact: AM / PM / Evening

Postal Address

Appendix A.3 Letter in the envelope for participants

The study: “An analysis of the challenges and stressors experienced by the parents of children with neurodevelopmental conditions at different transitional stages”.

Dear

Thank you for showing an interest in the above study.

I would like to invite you to take part in a Cerebra-funded (PhD) research study, investigating stress in parents of children with neurodevelopmental disorders.

The research is being conducted at Swansea Metropolitan University, as a part of a PhD study and is being supervised by Dr Ceri Phelps and Prof. Ann Edworthy. As a part of this research I would like to obtain the views of as many parents as possible to ensure that we have a fairly representative sample covering children of various age groups and both genders.

We are hoping that this study will help us identify ways of helping parents of children with neurodevelopmental disorders in future.

To read further about the details of the study, please find enclosed the study information sheet we have enclosed with this letter. I hope this will clarify any questions you may have. If you still have concerns, please contact me as soon as possible, using the contact details given in the information sheet.

Please remember that taking part in this study is voluntary.

Yours sincerely,

Payal Sood.

Research Assistant.

Appendix A.4

Interview Schedule (Study One: Qualitative IPA)

- Can we please begin by talking about your child? Or
- Can you please tell me about (name of the child)?
- Prompts if needed: their diagnosis, age, time since they received the diagnosis and the child’s general well being
- Has their diagnosis changed your life in any way?
- Can you please tell me about your role as a parent to (child’s name)? or
- How do you feel about your care giving or parenting responsibilities about her or him?
- Do you feel supported in this role?
- Prompt: are your family etc helpful or supportive (partner, family, friends, colleagues etc).
- Do these caregiving duties make you more prone to stress in comparison to other parents?
- What makes you most stressed about the position you are in?
- Prompts: the child’s health or behaviour for example, lack of help from others etc..
- In what ways has looking after (child’s name) changed your life?
- Prompt: in ways it has made life more positive. Do you think you cope better with situations now?
- Has your role as (child’s name) mother / father changed you in any way?
- Has it made you any stronger or weaker as a person in any way?
- Please elaborate, or if you share a few examples

- As your child is growing do you think the situation changes in any way for yourself as the parent?
- Such as care giving duties, the kind of help or assistance they may need from you?
- What are your thoughts on the key developmental stages in terms of dealing with them i.e is any stage according to your opinion more or less stressful than another, e.g. starting school, becoming a teenager etc.
- Do you worry about these developmental stages or do they specifically stress you?
- If Yes: please elaborate, reasons, how will you or in the past how have you dealt with them?
- If no: so there is no additional stress specifically related to key developmental stages?
- How do you cope with the day to day stress in parenting?
- Or Are there different ways that you cope with your stress?
- Which of these works best for you ? Is there one way better than the other?
- Is there a specific coping technique you use to relax? or
- Or can you please give me an example of how you cope or relax or atleast try to relax, anything specific you do to calm yourself down in a stressful situation?

Appendix B.1 Draft Coping Leaflet

Draft Coping Leaflet Getting through your day…..

We know from our experience that there are many worries, frustrations and difficulties faced everyday by parents and carers of children with neurodevelopmental conditions. We also know that many people have developed different strategies that help them through the day.

If you already feel that you have developed good ways of coping with the different challenges each day brings, then the advice in this leaflet is perhaps not for you. However, if you do feel some worries or concerns, then some of the advice here may help.

Coping with daily worries

Taking time out

Taking time out – even for five minutes – may often feel like an impossible task, or one which you may feel guilty about. We know, however, that doing something as simple as taking a "breather" for a few minutes a couple of times a day can help you feel calmer and stronger. You probably even do this already!

Getting things out of your head

Although it may feel like the last thing you want to do after a stressful day, it is worth spending a few minutes each day writing down how you feel about your day. What you write may be as sensible or crazy as you like. The important thing is that you write down whatever is in your head, at that time - no one else need know what you are thinking or feeling!

Benefit-Finding

You may not always think so but it is often possible to identify some positive things – however small – that have happened during a stressful day. Try to think of some of these and then remember these every time a worry or negative thought comes to mind. You may not be successful every time, but keep trying. The more you use them, the easier you will find it to use them, and you may find that thinking about these things helps you feel better able to cope with the difficult things.

Identify one or two positive things that have happened to you today and write them in the box below - a smile from someone, a nice cup of tea, a calm moment, or simply getting through to the end of the day!

Distracting from your worries

Worry can be like a habit. It can intrude at times when the last thing you want to do is think about something. But like any other habit, it can be prevented by putting something in its way or by doing things that help you control those worries. Here are some simple strategies that may work for you:

- Count to 50, while imaging the numbers in your head
- Think of a calm or favourite place
- Talk to someone about anything other than the worry on your mind
- Absorb yourself in something interesting or fun to do

Different strategies may work for different people and at different times of the day – keeping busy may be more helpful in the day, thinking of a favourite place may be more helpful at night. The important thing now is to find one or more strategies that work for *you*.

Worries about the future

While it can be distressing to worry about the future, some people may still find they want to think about the future and plan for its possibilities. The techniques we have described do not mean that you cannot do this. However, they do allow you to control the times you think about the future and prevent thoughts coming unwanted to mind.

If there are times that you do want to think about the future, then do so. However, we recommend that you set times back in the day to think about things, say for ten to twenty minutes, and then make use of some or all of these strategies at all other times. In this way, you control your worries, not they control you.

Remember – different strategies may work for different people and at different times of the day – The important thing now is to find one or more strategies that work for *you*.

Appendix B.2

PRIFYSGOL CYMRU
Y Drindod Dewi Sant
UNIVERSITY OF WALES
Trinity Saint David
SWANSEA - ABERTAWE

Study information sheet

A qualitative study to explore the acceptability and potential effectiveness of a coping leaflet for parents of children with neurodevelopmental conditions.

We would like you to take part in our research study. Please read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information please contact Payal Sood on 01792 482084. Please take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

- We have developed a coping leaflet that we hope might help parents who are looking after children with neurodevelopment conditions to cope with the daily challenges that they face
- We need to find out what parents think of this coping leaflet, whether they would make use of it and if they would find it helpful.
- To this we are hoping to ask a small number of people to agree to take part in this study and to make use of the coping leaflet for two weeks and then to give us some feedback about it.
- This study forms part of a PhD for Mrs Payal Sood, who is studying at the School of Psychology, University of Wales Trinity Saint David, Swansea.

How do I agree to take part in this study?

- Taking part in the study is voluntary and it is up to you to decide whether to take part.
- If you decide to take part you will be given this information sheet to keep and be asked to sign and return the consent form.
- If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

- Once we receive your consent form the researcher will contact you on the phone or by email to discuss the study in more detail and answer any questions you may have.

- You will then receive a copy of the coping leaflet and information about what we would like you to do over the two-week period of the study.
- The researcher will ring you at the end of the first week to see how you are getting on with the leaflet
- At the end of the two week period we would then like to hold a telephone / face to face interview with you to ask you questions about what you liked and didn't like about the coping leaflet. This interview will be arranged at a time convenient to you and should last no longer than 30 minutes
- The interview will be tape recorded, transcribed and analysed for the purposes of the research.

Will my taking part in this study be kept confidential?

- All information will remain strictly confidential
- Interview data will be recorded and transcribed. Only the researchers will have access to the tapes and transcriptions, which will be kept in a secure place and will be destroyed at the end of the research, one year after publication.
- Participants' names will be anonymised in any published excerpts of the transcripts.
- At no time will your data be passed on for any other purpose unless there are significant concerns about your safety or the safety or others or through other legal requirements.

What if I change my mind about taking part or if something goes wrong?

- Participating in this study only requires you to use the coping leaflet over a two week period and then to talk to the researcher about what you think about the leaflet. It is therefore highly unlikely that anything should go wrong.
- You can change your mind about taking part in the study at any time by contacting the researcher on the details below.
- You can also choose to stop the interview at any time if you do not wish to continue.
- If you are not happy about any part of the study then you can contact the Academic Supervisor Dr Ceri Phelps on the details below.

What will happen to the results of this part of the research study?

- The results of this phase of the study will form part of a higher degree thesis (PhD). The results may also be published in a relevant journal.
- The leaflet will be improved in the light of feedback provided by the participants. The impact of the revised leaflet will then be evaluated in a second questionnaire study.

- It is hoped that the final leaflet will eventually be available for use for parents caring for children with neurodevelopmental conditions throughout the UK who wish to mediate their levels of stress.

Who has reviewed the study?

- This study has been reviewed approved by University of Wales Trinity Saint David's Research Ethics Committee.

Contact for further information

- If there is anything that is not clear or you would simply like more information, please contact Payal Sood using the following contact details:

Payal Sood

Room TA103

School of Psychology & Counselling

University of Wales Trinity St David

Townhill Campus

Townhill

Swansea SA2 0UT

Tel: 01792 482084

Email: psood.128328@student.uwtsd.ac.uk

- If you would like to contact the academic supervisor please contact:
Dr Ceri Phelps

School of Psychology

University of Wales Trinity Saint David

Townhill Campus

Swansea SA2 0UT

Tel: 01792 482084

Email: ceri.phelps@uwtsd.ac.uk

Appendix B.3 Draft Topic Guide

PRIFYSGOL CYMRU
Y Drindod Dewi Sant
UNIVERSITY OF WALES
Trinity Saint David
SWANSEA - ABERTAWE

- Have you read and made use of the coping leaflet over the last two weeks?
  How much – can you tell us how often

  If no – can you tell us why not?

- Have actually tried out some or all the techniques explained in the leaflets?
  YES: Did they work? Which ones? What did you think of the techniques?

  NO: Why not?

- What was your overall impression of the leaflets?
  Prompt – good idea/bad idea?
  - How easy did you think the leaflet was to read?
  - Are there any specific changes /additions that you think would make the leaflet better?

- Have you shown or discussed the leaflet with anyone else – who – what did they think of it?

- How likely would you be to use the techniques in the leaflet in your day to day lives?

  Prompt for explanations………why/tell me more/can you explain

- Do you think you would try using these techniques in the future if you found yourself worrying about something else?

  Prompt for explanations………why/tell me more/can you explain

- Are there any other ways of helping you cope with your worries or anxieties that you feel may be better/more effective?

- Any ideas about the visual presentation of the leaflet which you think might make people more likely to read/use it? e.g. colours, size, laminated etc?

Would you prefer if we had an online version for eg access on your ipad smart phone etc?

Appendix B.4 Final Self-help coping leaflet

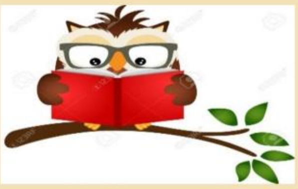
Getting through your day…..

We know from our experience that there are many worries, frustrations and difficulties faced every day by parents and carers of children with developmental disabilities. We also know that many people have developed different strategies that help them through the day. However, if you do feel some worries, or find it hard to cope sometimes, then some of the advice here may help. Remember – **different strategies may work for different people and at different times of the day – The important thing now is to find one or more strategies that work for *you*.**

Coping with daily worries

1. TAKING TIME OUT

Taking time out – even for five minutes – may often feel like an impossible task, or one which you may feel guilty about. We know, however, that doing something as simple as taking a "breather" for a few minutes a couple of times a day can help you feel calmer and stronger. Have a cup of tea, sit in the garden, watch the nature if not the tele…just take a little break doing nothing!



2. GETTING THINGS OUT OF YOUR HEAD

Although it may feel like the last thing you want to do after a stressful day, it is worth spending a few minutes each day writing down how you feel about your day. What you write may be as sensible or crazy as you like. The important thing is that you write down whatever is in your head, at that time - no one else need know what you are thinking or feeling! Have a go writing about your feelings in a diary or journal!

3. BENEFIT-FINDING

You may not always think so but it is often possible to identify some positive things – however small – that have happened during a stressful day. Try to think of some of these and then remember these every time a worry or negative thought comes to mind. You may not be successful every time, but keep trying. The more you use them, the easier you will find it to use them, and you may find that thinking about these things helps you feel better able to cope with the difficult things. Identify one or two positive things that have happened to you today and think of them- a smile from someone, a nice cup of tea, a calm moment, or simply getting through to the end of the day!

4. DISTRACTING FROM YOUR WORRIES

Worry can be like a habit. It can intrude at times when the last thing you want to do is think about something. But like any other habit, it can be prevented by putting something in its way or by doing things that help you control those worries at certain times of the day or night. Here are some simple strategies that may work for you:

- Count to 50, while imaging the numbers in your head
- Think of a calm or favourite place
- Talk to someone about anything other than the worry on your mind
- Absorb yourself in something interesting or fun to do

In this way, you control your worries; not they control you.

Appendix B.5 Instructions

PRIFYSGOL CYMRU
Y Drindod Dewi Sant
UNIVERSITY OF WALES
Trinity Saint David
SWANSEA - ABERTAWE

Instructions for using the coping leaflet

The coping leaflet suggests the use of various strategies to deal with some of your worries on a daily basis, please take time to read these carefully and try to make use of ANY of these strategies everyday use for the next two weeks.

It is NOT necessary that you use all the techniques/ strategies mentioned on the leaflet everyday , you may wish to one , two or more depending on what works best for you on the day; however, it is important that you aim to use AT LEAST ONE of the mentioned techniques each day if you can.

Taking Time Out: Just taking a breather for yourself, maybe a few relaxing minutes (5-10 mins) for a cup of tea or coffee, watching the tele, or a power nap!

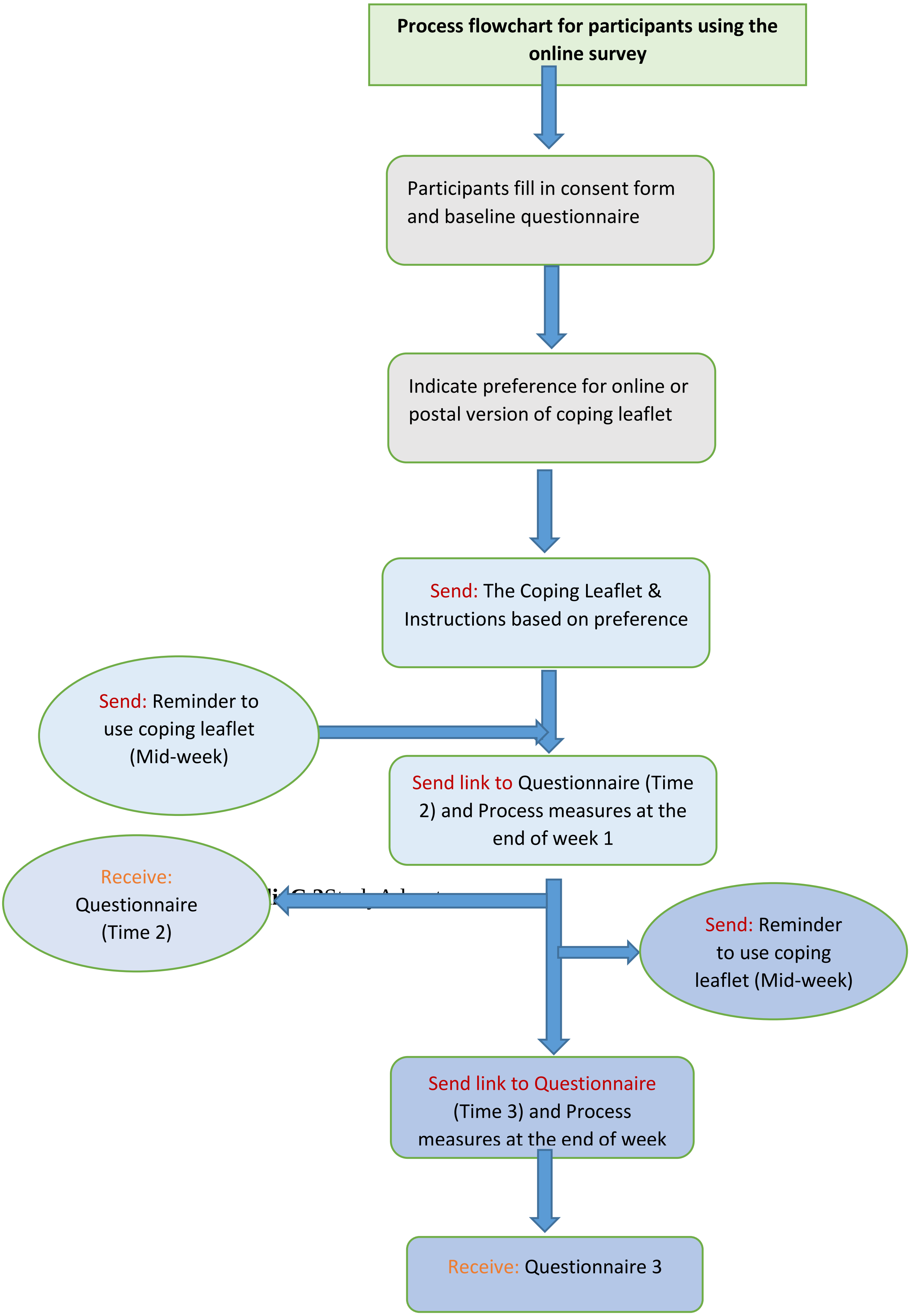
Getting things out of your head: Writing down whatever you want to for no one to read!

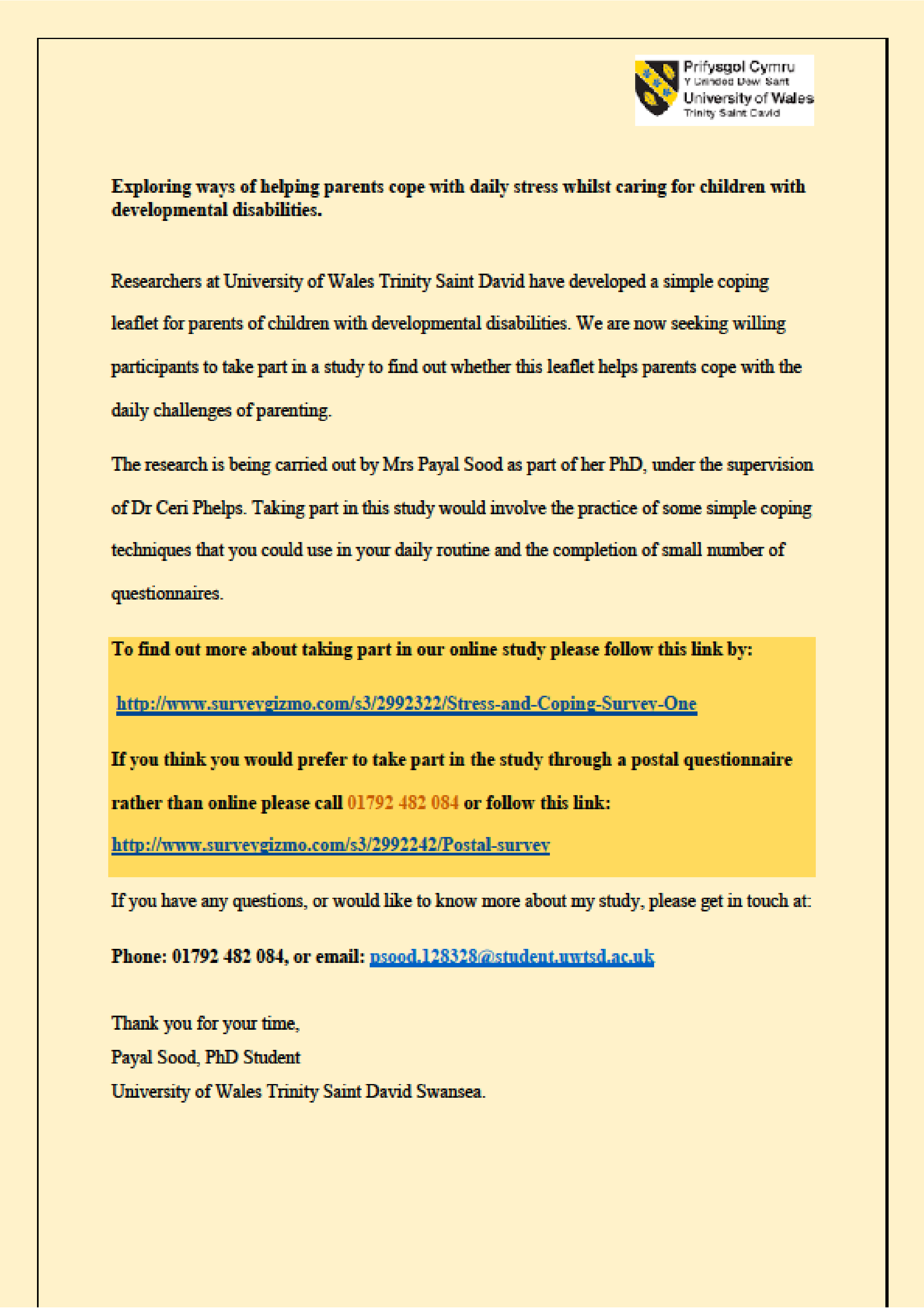
Benefit finding: Think of at least two positive things/ blessings each day, you can write them down if you want to!

Distraction from worries: Try to control your worries by distraction, think of things which can engross your brain and divert attention from intrusive thoughts!

Worries about the future: Set certain times of the day to think about the future, do not let the worries of the future impede your present. Postpone worries to think about their solutions at set times!

Appendix C.1 Process flowchart





Prifysgol Cymru
Y Drindod Dewi Sant
University of Wales
Trinity Saint David

Exploring ways of helping parents cope with daily stress whilst caring for children with developmental disabilities.

Researchers at University of Wales Trinity Saint David have developed a simple coping leaflet for parents of children with developmental disabilities. We are now seeking willing participants to take part in a study to find out whether this leaflet helps parents cope with the daily challenges of parenting.

The research is being carried out by Mrs Payal Sood as part of her PhD, under the supervision of Dr Ceri Phelps. Taking part in this study would involve the practice of some simple coping techniques that you could use in your daily routine and the completion of small number of questionnaires.

To find out more about taking part in our online study please follow this link by:

http://www.surveygizmo.com/s3/2992322/Stress-and-Coping-Survey-One

If you think you would prefer to take part in the study through a postal questionnaire rather than online please call 01792 482 084 **or follow this link:**

http://www.surveygizmo.com/s3/2992242/Postal-survey

If you have any questions, or would like to know more about my study, please get in touch at:

Phone: 01792 482 084, or email: psood.128328@student.uwtsd.ac.uk

Thank you for your time,
Payal Sood, PhD Student
University of Wales Trinity Saint David Swansea.

Appendix C.3 Consent form

1. I confirm that I have read and understood the information provided for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
*

○ Yes

○ No

*2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.**

○ Yes

○ No

3. I understand that any information given by me may be used in future reports, articles or presentations by the research team.
*

○ Yes

○ No

4. I understand that my name will not appear in any reports, articles or presentations.
*

○ Yes

○ No

*5. I confirm that I am over 18 years of age.**

○ Yes

○ No

6. I agree to take part in the above study.
*

○ Yes

○ No

Please enter your date of birth by selecting a date from the corresponding calendar, **this will be used as your** Respondent ID**.**

Appendix C.4 Demographic Information

Your Age:

- ○ 16-24
- ○ 25-34
- ○ 35-44
- ○ 45-54
- ○ 55-64
- ○ 65+

Your Gender:

- ○ Female
- ○ Male
- ○ other

Your relationship with the child?

- ○ Mother
- ○ Father
- ○ Grandmother
- ○ Grandfather

How many children do you have?

Marital or Family status:

- ○ Married

○ Separated/ Divorced

○ Civil Partnered

○ Cohabiting (living with your partner)

○ Widowed

○ Single parent

Level of formal education

○ University degree or higher

○ Higher education

○ A Level or equivalent

○ GCSEs or equivalent

○ Other qualifications

○ No qualification

○ Don't know

Approximately, how long has it been since you received diagnosis for your child?

○ Within the last 12 months

○ Within the last five years

○ Within the last ten years

○ Within the last fifteen years

○ Over fifteen years

What is your child's age? (please specify months or years)

What is your child's gender

○ Female

○ Male

○ Prefer not to disclose

To what extent ***do you consider yourself to be a 'single parent'*** *i.e. providing maximum care for your child by your own most of the times without having the opportunity to share caring responsibilities?*

○ Almost always

○ Very often

○ Sometimes

○ Rarely

○ Never

Appendix C.5 Perceived Stress Scale (PSS-10)

In the past month, how often have you been upset because of something that happened unexpectedly?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you felt unable to control the important things in your life?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you felt nervous or stressed?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you felt confident about your ability to handle personal problems?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you felt that things were going your way?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you found that you could not cope with all the things you had to do?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you been able to control irritations in your life?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you felt that you were on top of things?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you been angry because of things that happened that were outside of your control?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

In the past month, how often have you felt that difficulties were piling up so high that you could not overcome them?

○ Never

○ Almost Never or rarely

○ Sometimes

○ Fairly Often

○ Very Often

Appendix C.6 Brief COPE

I've been turning to work or other activities to take my mind off things

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been concentrating my efforts on doing something about the situation I'm in.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been saying to myself "this isn't real."

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been using alcohol or other drugs to make myself feel better.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been getting emotional support from others.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been giving up trying to deal with it.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been taking action to try to make the situation better.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been refusing to believe that it has happened.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been saying things to let my unpleasant feelings escape.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been getting help and advice from other people.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been using alcohol or other drugs to help me get through it.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been trying to see it in a different light, to make it seem more positive.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been criticizing myself.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been trying to come up with a strategy about what to do.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been getting comfort and understanding from someone.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been giving up the attempt to cope.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been looking for something good in what is happening.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been using humour to make the situation light.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been accepting the reality of the fact that it has happened.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been expressing my negative feelings.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been trying to find comfort in my religion or spiritual beliefs.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I’ve been trying to get advice or help from other people about what to do.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been learning to live with it.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been thinking hard about what steps to take.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I’ve been blaming myself for things that happened.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been praying or meditating.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

I've been using humour to deal with the situation.

○ I haven't been doing this at all

○ I've been doing this a little bit

○ I've been doing this a medium amount

○ I've been doing this a lot

Appendix C.7 Parental Distress; Parenting Stress Index (PSI)

I feel that I cannot handle things.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I have given up my own life for my child's needs.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I feel trapped by my parenting responsibilities.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I am unable to do new and different things.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I am never able to do things that I like to do.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I am unhappy with last purchase of clothing for myself.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

There are quite a lot of things that give me a reason to worry.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

Having a child caused problems with spouse or partner.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I feel alone and without friends.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I expect that I will not enjoy myself at parties.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I am not as interested in people as I used to be.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

I don’t enjoy things the same way as I used to.

○ Strongly Agree

○ Agree

○ Not sure

○ Disagree

○ Strongly Disagree

Appendix C.8 Other information and free text

If you would like to tell us anything else about your parenting role please feel free to write in the box below.

Thanks for answering all the questions!

In order for us to send you the ***Coping Leaflet*** *please provide us with your residential address, or, alternatively, if you prefer an online or pdf version of the leaflet please provide us with your email address:*

Name:

Address Line 1:

Address Line 2:

Town or City:

County:

Postcode:

In order for us to send you the link to the next questionnaire (approximately after one week), it is important that you please provide us with your email address.

Email:

Please confirm Email:

If you wish us to send you text reminders regarding filling in the questionnaires and using the coping leaflet please provide us with your mobile number. (We will only be sending you only two text messages over a two week period while you are still taking part in the study).

Mobile Phone number:

Appendix D.1

Master Table of Superordinate and Subordinate Themes

Superordinate theme	Subordinate theme	Example Quote	Illustration
Playing a special role	The paradox of love and hate	*Sometimes I love it sometimes I hate it…hmmm.. I get very frustrated….. tired both physically and mentally*	Too much physical exhaustion
	The feeling of being the 'sole' provider	*We are on duty 24 hours a day 7 days a week (line 15:01) 6*	Constant demands
	Taking a different path in parenting	*The one thing I worry about most is her vulnerability* *…he is only little still got an incredible strength when he gets bigger so that worries me*	Child behaviour and Diagnosis: Vulnerability, increasing physical strength

Enhancing Inner strength and Resilience	Developing the self	*Honestly, it has made a much more stronger person than I ever was having P has made me identify strengths I never knew I had…*	Acquiring strength over time
	Constant feeling of obligation	*…it does make me feel very stressed but I have to carry on because there is no one else who will look after him*	Lack of choice
Private Burden=Private Coping	Taking 'a miss ' for a while	*…. I don't know, I don't know.. how will I explain this to her, how hard will it be…. Don't want to think about it yet, honestly.* *. I do go on the internet at times and have found many*	Avoidant coping

	Learning to deal better	*useful tips from bloggers, and certain websites which are very useful, they share very useful tips and information.*	Problem focused coping
	Having guilt free moments	*… I go walking actually, that’s how I deal with my stress. I walk really far I’ve just got a new puppy whose and we walk, we walk and we walk and it helps*	Me-Time or Distraction
	Combining the best of all	*… I try not to keep it to myself, I talk about my worries with people who can help…*	Mixed coping methods
Discontentment and Isolation	Solitary Burden	*…I have forgotten somehow to go out with a crowd of people and to chat*	Feeling of isolation

	Falling in a vicious circle of systems	*…you're being passed from pillar to post with Cahms and schools, it's a nightmare absolute nightmare.(46-47, p02)*	Dissatisfaction with the services
Positive Outlook = Positive Adaptation	Transforming the self	*…always look for positives cause in any situation there is a positive I think.*	Developing a positive approach
	Changing perceptions	*…I am happy with the way things are, they could have been a lot different but not better…*	Acceptance of the situation

Appendix D.2 Table: list of the scales combined into 3 categories (Brief COPE).

Scales	**Items**
Problem Focused	
Active coping, items 2 and 7	I've been concentrating my efforts on doing something about the situation I' I've been taking action to try to make the situation better.
Use of instrumental support, items 10 and 23	I’ve been getting help and advice from other people. I’ve been trying to get advice or help from other people about what to do.
Planning, items 14 and 25	I've been trying to come up with a strategy about what to do. I've been thinking hard about what steps to take.
Active Emotion	
Self-distraction, items 1 and 19	I've been turning to work or other activities to take my mind off things. I've been doing something to think about it less, such as going to movies,
Use of emotional support, items 5 and 15	I've been getting emotional support from others. I've been getting comfort and understanding from someone.
Venting, items 9 and 21	I've been saying things to let my unpleasant feelings escape. I've been expressing my negative feelings.
Positive reframing, items 12 and 17	I've been trying to see it in a different light, to make it seem more positive. I've been looking for something good in what is happening.
Humor, items 18 and 28	I've been making jokes about it. I've been making fun of the situation.
Acceptance, items 20 and 24	I've been accepting the reality of the fact that it has happened. I've been learning to live with it.
Religion, items 22 and 27	I've been trying to find comfort in my religion or spiritual beliefs. I've been praying or meditating.
Avoidance Coping	
Denial, items 3 and 8	I've been saying to myself "this isn't real.” I've been refusing to believe that it has happened.

Substance use, items 4 and 11	I've been using alcohol or other drugs to make myself feel better. I've been using alcohol or other drugs to help me get through it.
Behavioral disengagement, items 6 and 16	I've been giving up trying to deal with it. I've been giving up the attempt to cope.
Self-blame, items 13 and 26	I’ve been criticizing myself. I’ve been blaming myself for things that happened.

Appendix D.3 Table of Respondent profiles

Characteristics	**Number of Participants (n=88)**
Age (16-24)	2 (2.3 %)
Age (25-34)	18 (20.5%)
Age (35-44)	47 (53.4%)
Age (45-54)	19 (21.6%)
Age (54+)	2 (2.3%)
Gender Female (mothers)	83 (94.3%)
Male (fathers)	5 (5.7%)
Number of children* (1-3)	77 (87.5%)
Number of children (5-8)	10 (11.3%)
Marital status Married	51 (58%)
Cohabiting	18 (20.5%)
Single	13 (14.8%)
Separated	6 (6.8%)
Formal Education University or higher	42 (47.7%)
Higher Education	11 (12.5%)
A levels or GCSE	31 (31%)
Other or no qualification	03 (3.4%)
Diagnosis* Within last 12 months	20 (22.7%)
Diagnosis within last 5 years	44 (50%)
Diagnosis in the last10 years	14 (15.9%)
Diagnosis in the last 15 years or more	9 (10.2%)
Gender* Child Male	56 (63.6%)
Child Female	30 (34.1%)
Single Responsibility* Always or very often	43 (48.9%)
Rarely or never	23 (26.1%)

*Totals do not add up to n=88, as participants chose not to answer some of these questions.

Co Appendix D.4

C Component Matrix[a]

	Component								
	1	2	3	4	5	6	7	8	9
I taking action to try to make the situation better	.740					-.342			
I've been giving up trying to deal with it	-.704								
I've been trying to come up with a strategy about what to do	.662			.431					
I've been thinking hard about what steps to take	.631			.359					
I've been giving up the attempt to cope	-.565			.424					
I've been concentrating my efforts on doing something about the situation I'm in	.549	.380				-.315			
I’ve been criticizing myself	-.521			.516				-.374	
I’ve been trying to get advice or help from other people about what to do	.486	.458	.364		.340				
I've been accepting the reality of the fact that it has happened	.471				.379				
I've been looking for something good in what is happening	.459			.324		.335			-.372
I've been learning to live with it	.378		-.345	.347	.307				
I've been using humour to make the situation light		-.774							.331
I've been using humour to deal with the situation		-.702							.311
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping		-.484	.421				-.373		
I’ve been getting help and advice from other people	.347	.451	.400						
I've been saying things to let my unpleasant feelings escape		.429		.413					
I've been trying to find comfort in my religion or spiritual beliefs			-.601		.337	.338			
I've been praying or meditating			-.576			.461			
I've been expressing my negative feelings			.490	.415					
I've been getting comfort and understanding from someone	.372		.461			.434			
I’ve been blaming myself for things that happened	-.451			.606					
I've been using alcohol or other drugs to make myself feel better	-.362		.370		.690				
I've been using alcohol or other drugs to help me get through it	-.349		.417		.674				
I've been getting emotional support from others			.466			.541			
I've been refusing to believe that it has happened							.631		
I've been saying to myself this isn't real		.338					.455	.578	
I've been turning to work or other activities to take my mind off things		-.407						.559	
I've been trying to see it in a different light, to make it seem more positive	.457					.314			-.596

Extraction Method: Principal Component Analysis.

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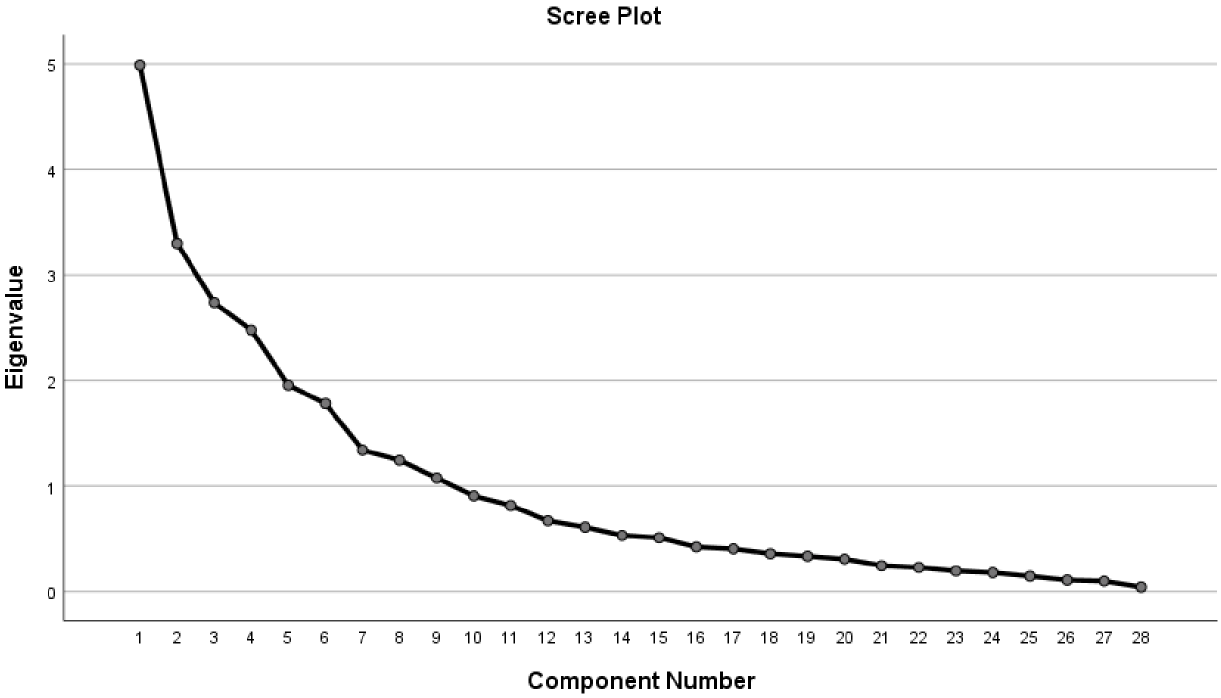
Appendix D. 4



Appendix D.5 Table: Process measures of coping leaflet at Time Two and Time Three

Question	Valid N	Response Options	N	Valid percentage %
How many days did you use the coping leaflet in a week?	N= 37	Once in a week	12	32.4
		Twice in a week	6	16.2
		Three times in a week	4	10.8
		Four times in a week	4	10.8
		Five times in a week	7	18.9
		Everyday	4	10.8
Time spent on practising the techniques mentioned in the leaflet each time you used it	N= 37	Less than 10 minutes	10	27.8
		10-20 minutes	25	69.4
		More than 20 minutes	1	2.8
Taking time out	N= 37	Yes	33	89.2
		No	4	10.8

Writing about your feelings	N= 37	Yes	6	83.8
		No	31	16.2
Benefit finding	N= 37	Yes	15	40.5
		No	22	59.5
Distracting from your worries	N= 37	Yes	25	67.6
		No	12	32.4

Process measures of coping leaflet at Time 3

Question	Valid N	Response Options	N	Valid percentage %
How many days did you use the coping leaflet in a week?	N= 21	Once in a week	6	28.6
		Twice in a week	7	33.3
		Three times in a week	5	23.8
		Four times in a week	1	4.8
		Five times in a week	1	4.8
		Everyday	1	4.8
Time spent on practising the techniques mentioned in the leaflet each time you used it	N= 21	Less than 10 minutes	8	38.1
		10-20 minutes	10	47.6
		More than 20 minutes	3	14.3
Taking time out	N=21	Yes	18	85.7
		No	3	14.3

Writing about your feelings	N= 21	Yes	5	23.8
		No	16	76.2
Benefit finding	N= 21	Yes	13	61.9
		No	8	38.1
Distracting from your worries	N= 21	Yes	13	61.9
		No	8	38.1