

Mediators of coping in caregivers of children with complex needs

Carol Delaney

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Abstract:

Mediators of coping in caregivers of children with complex needs and factors associated with coping has rarely been investigated in the past. A systematic review of the quantitative caregiver coping literature indicated that previous research had a specific focus on individual conditions with inconsistent approaches towards participants, conditions and coping measures. A quantitative online questionnaire was created which incorporated tools to measure Coping and potential mediators of coping: Adult Attachment, Emotion Regulation and Cognitive Fusion. Data were also collected on type, severity and the number of children and types of conditions. Sample consisted of 121 caregivers from the UK and ROI with an average age of 39.12. Caregivers children were classified as either no additional need (n=41), Non-Physical conditions (n=39), Physical conditions (n=12) or complex needs (n=29). The sample was categorised into a complexity group (n=56) or a non-complexity group (n=65) for analysis.

The aims were to investigate the common Coping strategies used by caregivers of children with complex needs and to explore mediators of coping in caregivers of children in complex need. Mediation analysis was carried out to investigate whether there was an association between Adult Attachment, Emotion Regulation and Cognitive Fusion, coping and complexity of need. Cognitive Fusion and Attachment Avoidance were found to mediate coping strategy usage. When Cognitive Fusion and Attachment Avoidance scores were high, Self-Punishment and Coping Avoidance usage increased. Lower scores in Cognitive Fusion significantly increased the use of Accommodation and Approach coping strategy use. A decrease in Attachment Avoidance scores was also associated with an increase in Self-Help coping strategy usage.

Results indicate that reduced Cognitive Fusion and attachment avoidance can enhance adaptive coping strategies of Accommodation and Approach. Reduction of Cognitive Fusion and Attachment Avoidance can lead to more adaptive and helpful coping strategies for caregivers of children with complex needs. Suggestions are made on how interventions addressing high Cognitive Fusion and attachment avoidance could improve adaptive coping in caregivers of children with complex needs. This research concludes that coping strategy choice is influenced by specific mediators in caregivers of children with complex needs and further study into coping mediators and complex needs and how it impacts on carers is highly recommended.

1. Introduction

1.1 Overview

Research into stress management and coping strategies in caregivers of children with medical, behavioural or developmental conditions is prolific but inconsistent, with approaches taken as varied as the conditions investigated. Although there is a large body of research into individual disorders and illnesses, coping in caregivers of children with multiple or co-morbid physical and developmental conditions is rarely considered. Caregivers of children with chronic illness have been indicated as experiencing greater general stress than caregivers of healthy children (Cousino & Hazan 2013; Grootenhuis & Last, 1997; Rodenburg & Dekovic, 2007; Stuart & McGrew, 2009; van der Veek, 2009). When caring for a child with additional care needs, stress has also been associated with the additional effects of the family environment such as psychological distress, family functioning and marital distress (see review Grootenhuis & Last, 1997). This study examines potential mediators of coping and how the mediators may influence coping strategies in caregivers of children with complex needs. This chapter highlights the lack of definition and identification of complex needs, considers how coping is defined and introduces the proposed mediators which may influence coping strategy choice.

1.2 Caregivers of children with additional care demands

The UK census of 2011 (Office of National Statistics, 2011) stated the population as 63.1M. Within the census, disability was described as “having any limiting long standing illness, disability or infirmity that leads to a significant difficulty with one or more areas of the individual life” (p97). The population census of 2010 indicated 3% of children under the age of 5 and 7% of children aged between 5 and 14 were classed as disabled. Mental health in children was not examined as a separate category in the 2010 population census. A separate survey by the Mental Health Foundation (2004) indicated one in 10 children aged between 1 and 15 years of age had a mental health disorder including conduct disorder (6%) and emotional disorders (4%) such as anxiety disorder (3%) and depression (1%), hyperkinetic disorder such as ADHD (2%). A

proportion of 1% had less common disorders such autism, tics, eating disorders and mutism. It is evident there are many children with either physical health disabilities or mental health issues in the UK, although a comprehensive breakdown which quantifies all physical and mental health difficulties has not yet been produced.

The number of children with both physical and mental health conditions remains unknown. There is no evidence regarding how many caregivers in the UK population look after children with overlapping conditions and are caring for children with mental health issues, behavioural problems and/or physical difficulties. Nevertheless, literature on stress and coping whilst caring for a child with physical conditions (Cousino & Hazan, 2013; Grootenhuis & Last 1997a) or mental health disabilities (Dabrowska, 2008; Stuart & McGrew, 2009) indicates higher stress for these populations.

The impact of children with multiple demands and their educational needs was studied in a comprehensive research project (Carpenter, 2011) which indicated there were 950,000 families in the UK with a disabled child, based on the Disability Discrimination Act (DDA) reports of 1995 and 2005. The project described disability as “children with a limiting longstanding (12-month duration or more) illness, disability or infirmity experiencing one or more significant difficulties or health problems” (Blackburn, Spencer & Reid, 2010, p.3). This secondary analysis of the Family Resource Survey from the Office of Population, Consensus and Surveys, based on DDA definition, concluded that the most commonly reported difficulties were with memory, ability to concentrate, communication and physical coordination. Complex difficulties based on the DDA definition indicated 35.2% of children experienced 2 to 4 difficulties in daily life and 13.3% presented with difficulties in 5 or more areas of daily living (Blackburn et al., 2010). Unfortunately, these figures describe only people with learning disabilities.

1.2.1 What are complex needs?

The definition of Complex Learning Difficulties and Disabilities (CLDD) from Carpenter's education report (2011) is one of conditions which "co-exist, overlap and interlock to create a complex profile" (p.2) and they

"present with a range of issues and combination of layered needs – e.g. mental health, relationships, behavioural, physical, medical, sensory, communication and cognitive" (p.2).

It is imperative to investigate the impact of caring for a child with CLDD on caregivers, not only in the education setting but also in the home environment. It is envisaged that results from such research will inform policy, service delivery and inform appropriate family support mechanisms.

Caregivers who care for one or more children with severe medical, behavioural and developmental conditions could utilise very different coping strategies to mitigate stress than a caregiver of a single child with a mild condition. For the purposes of this investigation, caregivers of children with combined physical and mental health conditions, as described within the CLDD definition above, have been categorised as having complex needs.

Within this study the characteristics of complex needs are interpreted as when caregivers have multiple childcare responsibilities, including a higher than average care requirement, incorporating severity and type of the child or children's conditions. These additional care requirements could include overlaps on physical and non-physical conditions which may increase the complexity level experienced, identified within a cumulative complexity score framework. This approach could capture the layered needs of children with conditions present in a complex profile. This perspective is in keeping with the CLDD definition of Complex needs.

In the following sections, the concept of coping will be explored and potential mediators of coping will be discussed.

1.3 What is coping?

Coping is typically described as a process of appraisal of a stressful event or environment, and Lazarus and Folkman (1984) defined stress as:

“a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being.” (p19)

Lazarus and Folkman (1984) described coping as a way of managing the demands of the environment or event and the emotions generated by the individual as a response to this environment. Cognitive appraisal is described as key to coping, although Lazarus and Folkman suggested that the agendas shaping appraisals may not always be easily accessible and could be below a person's awareness. Lazarus and Folkman (1984) proposed a process of primary then secondary appraisal followed by re-appraisal. The primary appraisal incorporates a judgement, assessing if the encounter being experienced is irrelevant, benign, positive or stressful. Once this appraisal is complete, the secondary stage is a decision about the coping strategy to be utilised. This process is followed by a re-appraisal, either based on new information or defensive reaction of the secondary stage. As stated, this process is often subconscious and is not static but under constant review and re-appraisal. Coping is therefore traditionally viewed as a transactional process called upon during stressful situations.

There are other many theoretical conceptualisations of coping such as McCrae and Costa's (1987) model which proposed that personality traits permeate appraisal and coping activities. Dispositional coping as suggested by Endler and Parker, 1990; Parker & Endler, 1992) as compared to situational coping (Glidden, Billings & Jobe, 2006; McCrae & Costa 1987), has also been debated as important to coping (Carver, Scheier & Weintraub, 1989; Lazarus & Folkman 1984; Folkman & Lazarus, 1980, 1988a; Moos & Billing, 1982). It was suggested that personality traits and coping dispositions both played roles in

situational coping in the study by Carver, Scheier and Weintraub (1989). These roles were perceived as working with each other rather than against each other. Bouchard, Guillemette and Landry-Leger (2004) suggested the relationship between dispositional coping and distress was partially mediated by situational coping, when they studied situational and dispositional coping and their relationship with other constructs.

Despite the suggestion that coping might have a dispositional, inherent element, the predominant view is that coping is a transactional mechanism to manage stress. The Folkman and Lazarus measure, which encapsulates this view on coping, the Ways of Coping (WOC) scale (1980), has been criticised for poor psychometric properties, unstable factor analysis and lack of cross-validation (De Ridder, 1997; Endler & Parker, 1990). It has also been viewed as simplistic in its binary trait approach and as lacking a dispositional dimension (Carver et al., 1989). In spite of these criticisms, it is still being used in relevant research.

In order to understand coping, other factors which may be related to the coping strategy and potentially employed by caregivers might be considered. However, most research focuses on identifying coping patterns rather than on how coping may be mediated by other factors. The next section will highlight potential mediators of coping and suggest their importance when attempting to understand coping in caregivers of children with complex needs

1.4 Mediators of coping

When caregiver coping is investigated, traditional measures such as Ways of Coping are routinely utilised (Mirsaleh et al., 2011; McConkey et al., 2008; Pisula & Kossakowska, 2010) Coping is typically broken into broad categories of externally driven emotion or problem based strategies, focusing on external actions and internal mechanisms or drives. Constructs which could have the potential to influence the external strategy choice are not considered.

This research proposes that internal thoughts, feelings and emotions of caregivers of children with complex needs could mediate the external coping strategy choice. Three constructs were chosen as they have potential to be powerful influencers. Cognitive Fusion was chosen as the mechanism to measure thoughts, Adult Attachment for internal feelings and Emotion Regulation for internal emotion. The next section describes these constructs and how they are typically utilised as measures to highlight the rationale behind choosing these potential mediators of coping within this investigation.

1.4.1 Attachment

In Bowlby's seminal work, attachment theory was defined as "adverse influences on personality development of inadequate maternal care during early childhood" (Bowlby, 1988, p.21). This lack of attachment bonds in the mother/child dyad was investigated by Bowlby and measures were developed to categorise different types of mother/child bonds. The first measure to categorise childhood attachment was the Strange Situation paradigm (Ainsworth & Bell, 1970). This observational study established three classifications of attachment including Secure Attachment, Ambivalent-Insecure attachment and Avoidant-Insecure. Attachment is now explored not only in the context of the internal working model, which a child forms as part of the relationship with their primary caregiver, but also in adult romantic relationships. Secure attachment is the most desirable stable state with avoidant-insecure, anxiety and ambivalence being contra-indicators of adaptive attachment styles in core relationships (Griffin & Bartholomew, 1994; Hazan & Shaver, 1987; Ognibene & Collins, 1998). Parental stress has been found to form associations with attachment styles such as avoidance (Rholes, Simpson & Friedman, 2006), fearful attachment (Vasquez, Durik & Hyde, 2002) and anxiety (Nygren, Carstensen, Ludvigsson & Sepa, 2012). Transmission of attachment is said to occur when a parent's cognitive model of adult relationship corresponds with the quality of the infant-parent relationship (Obegi, Morrison & Shaver, 2004).

The bridge between sensitivity responses in parents' and children's attachment and how parental attachment representations affect children's attachment

relationship is described as the transmission gap. The gold standard measure of attachment is the Adult Attachment Interview (AAI), George, Kaplan & Main, 1996). A meta-analysis of the AAI was conducted on 18 samples (N=854) indicating a combined effect size of 1.06 (indicated as a large effect) for the secure vs. insecure split (van IJzendoorn, 1995). The quality of the parent child attachment relationship was examined by considering the predictive validity as observed through the Ainsworth Strange Situation experiment and the correspondence between the parent's mental representation of attachment and the child's attachment security (N=661). Van IJzendoorn's (1995) meta-analysis indicated a predictive validity of the AAI of 75%. The conclusion of IJzendoorn's (1995) meta-analysis was that, although the AAI reports high predictive validity, knowledge on how attachment style relationships between parent and child are transmitted between each other and over generations is not adequately investigated.

The following sub-sections will describe how Attachment has been investigated in the literature in relation to caregivers of children with complex needs, coping and Emotion Regulation.

1.4.1.1 Attachment and caregivers of children with complex needs

A comprehensive search of inclusion of Adult Attachment measures being incorporated in the literature on coping in caregivers of children with additional needs did not yield many potential studies. In a qualitative study investigating the impact of induction or progression of diabetes-related autoimmunity through the AAI, 18 mothers of infants with diabetes were compared with 32 mothers of healthy children and no group differences were indicated (Sepa, 2004). No group differences were indicated either when studying insecure attachment as a mechanism for predicting psychological distress in 44 couples of children with congenital anomalies with 46 parents of healthy children (Fonseca et al., 2013). In another study, mothers of children (N=60) with recurrent bronchial asthma did however show a higher percentage of insecure attachment compared to a healthy control. (Cassibba, van IJzendoorn, Bruno & Coppola, 2004,). This would suggest that attachment style, in particular insecure attachment, has an impact on stress management and therefore may influence preferred coping

strategy, although these findings have not been typically employed as a line of enquiry in previous research.

1.4.1.2 Attachment and Coping

It has been suggested that insecure attachment is linked with less flexible coping in people with chronic disease. When coping and attachment were investigated in 150 patients with breast cancer, chronic leg ulcers and alopecia, insecure attachment was linked with less effective coping, suggesting secure attachment may be an important inner resource when coping with chronic disease (Schmidt, Nachtigall, Wuethrich-Martone & Strauss, 2002). In the same study, ambivalent attached individuals showed more negative emotional coping while avoidant attached individuals showed more diverting strategies. Secure attachment has also been linked to problem solving coping behaviours whereas avoidant attachment or the attachment factor of “discomfort with closeness” is associated with distancing coping behaviours as well as anxiety or ambivalent attachment styles (Alexander, Feeney, Hohaus & Noller, 2003). In a study of 145 students utilising attachment and coping measures, a repressive coping style was associated with more avoidant attachment indicators (Vetere & Myers, 2002). These studies would suggest insecure and avoidant attachment styles have associations with coping.

A secure primary relationship can be used as an indicator of individual and couple future functioning. The inherent response to stress, incorporating attachment style, can be seen as a critical organising construct in core relationship interactions (Feeney et al., 2003; Feeney, Noller & Hanrahan 1994). Low use of avoidant coping strategies and less avoidance in close relationships with significant others has been found to moderate the effect of children’s disabilities. The use of mothers’ strategies moderated the effect of the child’s disabilities on children’s level of loneliness, feelings of hope and secure attachment (Al-Yagon, 2007). The examination of the relationship between attachment and coping has rarely been examined in caregivers of children with either mental health or physical difficulties or both, although there are possibilities of links between these constructs. It would appear to be a good line

of enquiry to include adult attachment into this investigation into the role of how mediators could potentially influence coping strategy usage.

1.4.1.3 Attachment and Emotion Regulation

Emotion Regulation is a construct frequently utilised within studies and is typically defined as investigating management of inner feelings and how they are controlled and modified. This regulation and control of emotion is applied and investigated in studies across a range of situations and environments. Commonalities between adult attachment with Emotion Regulation and possible links to coping will be explored.

Emotion Regulation is defined as “the heterogeneous set of processes by which emotions are themselves regulated”, including “changes in emotion dynamics, or the latency, rise time, magnitude, duration, and offset of responses in behavioral, experiential, physiological domains” (Gross & Thompson 2007, pp. 7–8). Exploration of the caregiver/child bonds and the impact of caring on emotional regulation may have potential as a line of enquiry when investigating potential mediators of coping due to the suggested overlap with the constructs of adult attachment and Emotion Regulation.

In a review of the current perspective of the literature on Emotion Regulation and attachment by Shaver and Mikulincer (cited in Gross, 2014 p237-250) avoidant or anxious attachment styles were linked with deteriorating wellbeing and heightened distress. When attachment avoidance was present, factors such as “discomfort with depending on others” and a preference for “emotional distancing” were indicated as behavioural characteristics.

Attachment has been investigated in relation to caregivers of children with additional needs, coping and Emotion Regulation, but no studies were identified which combined these elements. The next section discusses the other mediators incorporated within this study. How coping combined with Emotion Regulation is investigated within the literature is discussed. The next stage of

the combination of coping, attachment and Emotion Regulation in relationship with each other is considered and discussed. The third mediator incorporated in the study, Cognitive Fusion, is then described and explained in relation to inclusion in this study as one of the potential mediators of coping. A proposed model of the role of mediators in the relationship between caregivers of children with complex needs and coping strategy usage is then presented.

1.4.2 Coping and Emotion Regulation

Emotion Regulation comprises a cognitive change through re-appraisal to change emotional meaning. This evaluation is similar to coping in that emotion is constantly being re-assessed, but different in that coping is typically portrayed as an action taken in response to a specific event or taxing environment, unlike Emotion Regulation. Coping with stress is predominantly portrayed as event specific and does not consider positive affect. In a study, which investigated if and why a specific coping mode was preferred in an authority conflict with parents, the indication was that goal framing created a mind-set affecting the content and purpose of coping strategies used (Boekaerts, 2002). Adolescents who matched their coping to fit their appraisal of control over stressful events showed fewer emotional and behavioural problems than those who reported mismatches. These findings indicated an interaction between emotion-focused coping and Emotion Regulation. In another study on individual differences and physiological factors which may influence Emotion Regulation and stress coping, it was found that individuals vary in their ability to regulate emotions and cope with stress, and these abilities may differ across age groups (Wang & Saudino, 2011). Activation of the hypothalamic-pituitary-adrenalin (HPA) axis has been linked with Emotion Regulation in children (Stansbury & Gunnar, 1994) and Emotion Regulation has been indicated as being able to predict elevations in cortisol levels (Zimmerman & Stansbury, 2004). These results suggest that coping and Emotion Regulation work together to formulate internal and external emotions which may influence the type of strategy chosen to manage stressful events or general day to day coping in the family environment. These links between coping strategy and Emotion Regulation indicate it could be a worthwhile line of enquiry to include in the investigation on coping in caregivers of children with complex needs.

1.4.3 Coping, Attachment and Emotion Regulation

There are certain overlapping coping aspects with both Emotion Regulation and attachment. The importance of studying the associations between coping and Emotion Regulation (Boekaerts, 2002; Wang & Saudino, 2011) or coping and attachment (Alexander et al. 2001; Schmidt et al., 2002) and Emotion Regulation and attachment (Shaver & Mikulincer, 2014) have been highlighted. Despite these bivariate associations being explored before, no previous studies were identified which investigated all these constructs in relation to coping, in a single study.

The present study was aimed at exploring potential mediators of coping, by examining interactions at a core emotional level. Psychological flexibility was also considered as a potential mediator of coping through incorporation of Cognitive Fusion within the study.

1.4.4 Cognitive Fusion

Cognitive Fusion is an element extrapolated from Cognitive Behaviour Therapy called Acceptance and Commitment Therapy (ACT), which aims at increasing psychological flexibility (Gillanders et al., 2010). The diffusion of cognitive thought is one of the six elements in ACT. Cognitive Fusion is viewed as a continuum and can range from “fused”, where thoughts are dominated, entangled, believed or taken literally when experiencing an emotional event to “defused”, where the person views the internal relationship as a mental event which may not require any action (Gillanders *et al.*, 2010). Gillanders et al. (2010) stated that how we relate to mental events is of critical importance to stress and coping. The Cognitive Fusion questionnaire was designed in order to build a better understanding of Cognitive Fusion and the rigidity of internal thought patterns.

The element of primary thought analysis, which has an internal and external appraisal element, would appear to have correlations with some attributes of attachment, Emotion Regulation and coping. Attachment is a core internal drive with key elements such as “need for approval” and “discomfort with closeness”.

These attachment elements could have similarities with the internal aspect of Cognitive Fusion, in that fused thoughts may correlate with attachment styles such as need for approval, resulting in dominated or entangled thoughts. Diffused thoughts could correlate with attachment measures such as “discomfort with closeness” or “relationships as secondary” as both processes are concerned with avoidance or reluctance to engage. In cognitive and external fusion, there is an element of regulation between the thoughts and the actions following appraisal which results in a possible action or the decision that action is not required. Cognitive Fusion can transform internal thoughts into decisions regarding possible action or inaction and has commonalities with Emotion Regulation and its main categories of suppression and appraisal.

The suggestion is therefore that, as Cognitive Fusion consists of exploring both internal and external thoughts and process, it may act as a mediator, influencing coping strategy usage. The Cognitive Fusion measure has been designed as “a brief, self-report measure of Cognitive Fusion of sufficient quality and flexibility in terms of item content and psychometric properties to facilitate its use in a variety of settings (clinical, community, laboratory), with many different populations” (Gillanders *et al.*, 2010, p.8). The flexibility of the Cognitive Fusion measurement was an additional benefit of utilisation within this study. The links with established therapies and the underlying concepts associated with internal thought processes, were also key for inclusion of Cognitive Fusion within the study and proposed model. Cognitive Fusion has not, to the researcher’s knowledge, been investigated in relation to coping combined with adult attachment or Emotion Regulation or with caregivers of children with any mental health or physical disabilities.

A recent study focused on the development of the cognitive fusion questionnaire found cognitive fusion and experiential avoidance were significantly associated (Gillanders *et al.*, 2014.). A Spanish version of the Cognitive fusion questionnaire was also found to be effective when studying dementia caregiving. Caregivers’ level of emotional distress was found to influence use of rumination and experiential avoidance maladaptive coping

strategies with cognitive fusion proposed as mediating caregivers coping strategy usage. (Romero-Moreno, R. et. al., 2014) Cognitive Fusion was also investigated as a mediator in a study on shame memories and depressive symptoms (Dinis, A. et al. 2015) Cognitive Fusion was found to impact depression symptoms indirectly through experiential avoidance. Although the Cognitive Fusion Questionnaire is an emerging measure the initial literature and the few studies available indicate it is an appropriate measure suited to this investigation.

1.5 The current study

The next chapter presents a systematic review on the existing literature on caregivers of children with additional needs. The review was conducted with the research aims in mind, as it is of vital importance to investigate how caregiver coping in additional needs is currently investigated. Although there was little evidence of caregivers of children with complex needs being identified or categorised, it may be that literature exists but the caregiver's children's needs are not defined using a readily identifiable term. A systematic review was the most efficient way of determining if complex needs had been investigated under a different categorisation. Data gathered would also build a picture of how coping in caregivers is traditionally investigated including aims, methodology, results and strengths and limitations. A systematic review would also provide an appraisal of any other study which may have considered mediators of coping. The potential mediators of coping chosen for this study did not appear to have been utilised when investigating caregivers of children with additional needs, but again the most robust way of confirming this was by conducting a systematic review cross-referencing all the variables. The systematic review was used to help answer the research questions.

After the systematic review, a proposed model of the role of mediators in coping in caregivers of children with complex needs is presented. The aims of the research are then described, followed by details of the quantitative experiment conducted for this study. The results are presented then discussed, with suggestions based on the potential implication of the findings.

2. Systematic Review

2.1 Aims

The aim of the systematic review was to summarise and critique evidence on the mediators of coping in caregivers of children with complex needs. There were two strands to this review. Coping in caregivers of children with any additional needs was investigated. The three potential mediators of coping: Adult Attachment, Emotion Regulation and Cognitive Fusion, were also reviewed to ascertain if any of these constructs were included when researching caregivers of children with an additional need. Identification of any studies which incorporated Coping measures with either Adult Attachment, Emotion Regulation or Cognitive Fusion were also sought for inclusion in the systematic review. This systematic review was conducted to ascertain how coping in caregivers of additional needs is currently investigated, evaluate approaches taken and establish the traditional approach of existing literature in relation to the aims, methodology and perspective of this study.

2.2 Design

This systematic review was drawn up using the PRISMA 2009 checklist as a guideline (Appendix 8.1). There were many elements of the PRISMA checklist (Moher, D. et. Al., 2009) which were not relevant for this study, however where applicable, the guidelines were adhered to. The participants, comparisons, outcomes and study design (PICOS) checklist points have been addressed in the four sections of Aims, Participants, Results and Strengths and Limitations. There was no similar review or protocol for this combination of subject areas. Information sources and search databases were identified and study selection and screening process documented. Data extraction method and variables at each level of selection were reported. Risk of bias has been addressed as much as possible by double checking data sets identified by filtering searches. Strict adherence to the inclusion and exclusion criteria has been followed to minimise bias. Flow diagrams are shown to indicate each stage of exclusion. Confidence intervals, forest plots and effect estimates are not relevant within the framework of this study.

In regards the search criteria, due to the lack of a widely-accepted definition and suspected lack of studies which addressed complex needs, it was necessary to start with search criteria using terms which could also incorporate complex needs. The search terms included searches on words such as cancer, autism and words like disorder and syndrome. A search on CINAHL, MEDLINE, PsychINFO and Psychology and Behavioral Sciences databases was conducted. The preliminary search (Table 1) was cross-referenced between main concepts (Table 2) with the use of an inclusion and exclusion criteria list (Table 3). The search was conducted in November 2012 and repeated in January 2013.

2.3 Search strategy

There were seven main search themes devised to capture the participants' condition, coping and its mediators. As shown in Table 2 below, searches S1, S6 and S7 identified the participants, S2 was used to identify the main coping criteria and S3, S4 and S5 identified potential mediators of coping. These main search groups were applied to create a working data file to allow subsequent searches within main results. Table 1 displays the number of records identified by each of these seven search groups. Duplicates were screened out automatically from the searches.

TABLE 1 Preliminary search conducted on main concepts of the study

No.	Search Items	Articles identified
S1	Caregiver OR Parent OR mother OR father OR Family OR Families OR child OR children OR infant	1,699,563
S2	Coping	127,221
S3	Attachment	117,771
S4	Emotion Regulation	7,666
S5	Cognitive Fusion OR acceptance commitment OR ACT	292,203
S6	Illness OR cancer OR diabetes OR epilepsy OR cerebral palsy OR sensory OR blind OR deaf blind children OR deafness OR physical OR handicap OR disabled	4,116,918
S7	Autism OR attention deficit OR disorder OR syndrome OR behavioural OR conduct OR developmental OR disabilities OR learning disabled OR condition	3,651,947

After this primary identification, the search groups indicated in Table 2 were then cross-referenced to extrapolate the required combinations as indicated in Table 3.

TABLE 2 Cross-referencing of preliminary searches for systematic review

Search number and measure	Cross reference search protocol	Records identified
S8 Coping	S1 AND S2 AND (S6 OR S7)	24,241
S9 Attachment	S1 AND S2 AND S3 AND (S6 OR S7)	525
S10 Emotion Regulation	S1 AND S2 AND S4 AND (S6 OR S7)	1,317
S11 Cognitive Fusion	S1 AND S2 AND S5 AND (S6 OR S7)	13,451

2.4. Inclusion and exclusion criteria

2.4.1 Criteria

An inclusion and exclusion Criteria Table was drawn up as described in table 3, to use as the template for identification of the studies and to utilise as the key point of reference applied during the searches:

TABLE 3 Inclusions and exclusions used in literature selection process

Inclusions	Exclusions
Quantitative studies	Qualitative or mixed methods studies where the results were reported combining both quantitative and qualitative analysis.
Caregivers of children up to age 18 with a physical, psychological or behavioural condition	Caregivers of children over the age of 18
Inclusion of a coping measure or investigating the association between coping and either attachment, Emotion Regulation or Cognitive Fusion.	Not individual coping, including: Coping as part of the family unit as indicated by family measurement or other measures not specifically measuring coping i.e. F-COPES, CHIP, PSI
Inclusion of a control group of caregivers of healthy/typically developed children or a comparison group of caregivers of children with another condition.	No comparison or control group included or between group comparisons such as age or gender
	A similar construct to coping was investigated, for example resilience, sense of coherence or hardiness including traits or behaviours rather than strategies.
	No access to the study as it was either written in a foreign language only or there was no availability
	Interventions or behaviour modification trials which included coping as an outcome measure
	Dissertations or any study not peer reviewed
	Literature reviews on the subject area

2.4.2 Exclusion procedure

Coping was considered in this study as it was described by Lazarus and Folkman (1984) as an interpretation of “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources“(1984, p19). The focus was on coping as a strategy or action utilised to manage the taxing environment, rather than an

inherent trait. The environmental aspects were investigated by considering the influences of different levels of severity and complexity of children's conditions. This was established so that the coping strategies caregivers may use to cope with their children's conditions could be measured, in relation to these aspects. It was not possible to search directly for complex needs due to the lack of use of a term such as "complex needs" or any other similar identifier of this population within the literature. To identify any potential studies which included or directly studied coping in caregivers of children with complex needs, an inclusion and exclusion criteria process was applied. Inclusion criteria included published, peer reviewed quantitative studies of individual caregivers of children under the age of 18 with any type of additional care need when compared to another condition or a control group. Included studies used a measure of coping, rather than similar constructs such as resilience, sense of coherence or depression. Studies which purported to measure coping but, on closer inspection, were merely similar to coping concepts such as burnout, sense of coherence, mindfulness or self-esteem, were excluded.

Studies which employed qualitative measures for coping were excluded, due to the difficulty of comparison with quantitative studies. Mixed measure studies were examined and if quantitative elements were reported individually without being combined with the qualitative measure, the study was included.

If a study focused on one condition or illness with no comparison with another condition or use of a control group, it was also excluded from the review. In studies involving a control group, ultimately more is learned about coping as it creates a contextual comparative foundation highlighting between-group differences. This level of analysis is not possible when coping in people with a specific condition are studied in isolation. Although studies on a specific condition can be very useful for ascertaining possibly unique condition specific behaviours or strategies, there are limitations to data results. Any caregiver behaviours, actions or strategy use could potentially be apportioned to individual caregiver similarities or differences within the participant sample and therefore the coping strategy usage may not be related to the child's condition.

The systematic review and the study were specifically looking to establish coping strategies of caregivers of children with additional needs and complex needs, therefore studies where no comparison was conducted were excluded.

Studies which included caregivers of those over 18 years of age were excluded, so that the focus was on caregivers of children, not adults caring for other adults. Any studies which used coping measures concerned with family coping as opposed to individual coping were also excluded.

2.4.3 Screening of identified papers

As it can be seen in Table 4, this first level of exclusion identified 14,303 studies for further analysis. Firstly, qualitative studies and non-published studies were removed. This was an automatic selection choice of the search criteria, so no visual check was required.

Detailed screening process to final selection stage of studies.

	records identified through database searching	after selection by quantitative excluding dissertations	records screened	Records excluded	full-text articles assessed for eligibility	Full text articles excluded	articles included in review
Coping	24,241	4,686	274	114	160	145	15
Attachment	525	85	7	5	2	1	1
Emotion Regulation	1,317	741	60	56	4	4	0
Cognitive Fusion	13,451	8,791	128	121	7	7	0
Total	39, 534	14,303	469	296	173	156	16

Secondly, exclusion criteria were applied as indicated in Table 3. This was conducted through a general analysis based on the title and abstract. The aim was to remove any studies identified by the search filters in Tables 1 and 2 which were not relevant to the context of the target population being investigated. The studies removed included papers on coping when caring for adults, adults coping with their own condition or illness and clinical trials where coping was referring to physical or genetic defence systems. Of the 14,303

studies, a total of 13,834 records were excluded based on the inclusion and exclusion criteria in Table 3. The remaining 469 records were then scrutinised in further detail by examining the full study on key points to establish elements such as the caregiver's child's age, presence of a control group or comparison condition, type of coping measures used and the other exclusion criteria as outlined in Table 3.

The 469 remaining studies were further scrutinised to confirm they were quantitative or included a quantitative coping measure. The records were then screened again and exclusions were made, dependent on inclusion of comparison group, age of children or access, as per Table 5. Studies that did not fulfil inclusion criteria were excluded from further analysis. A total of 16 studies met final inclusion and exclusion criteria, 15 related to coping and one study on adult attachment.

TABLE 5 Exclusion reasons for final 453 records in systematic review.

Exclusion reason	Number excluded
Qualitative	131
Not individual coping, including family coping and measures such as F-COPES and CHIP	141
No control or comparison group	123
Other: including age, access to study or if it was an intervention or a literature review	58
Total	453

Once the inclusion and exclusion process had been concluded, a hard copy of each study was printed and a full analysis summary sheet for the 16 studies was drawn up. Results were organised in terms of aims, participants, results, methodological strengths and limitations and theoretical approach.

2.5 Results

The next section presents the results of the systematic review. The coping studies were categorised by category then type of condition. There are sections on Coping in caregivers of children with Non-Physical conditions, Physical conditions, Undefined conditions and Combined conditions. To compare with these sections, similar conditions were compared and contrasted, for example, in the Non-Physical conditions category, one sub-section groups the studies on Autistic Spectrum and Down Syndrome together. The studies are all reviewed by Aims, Participants, Results and Strengths and Limitations. Summaries of these studies are presented at the end of each section. The next section after the Coping studies review are the search results for the potential mediators of coping; Adult Attachment, Emotion Regulation and Cognitive Fusion. A summary of the systematic review is then presented.

2.5.1 Coping studies

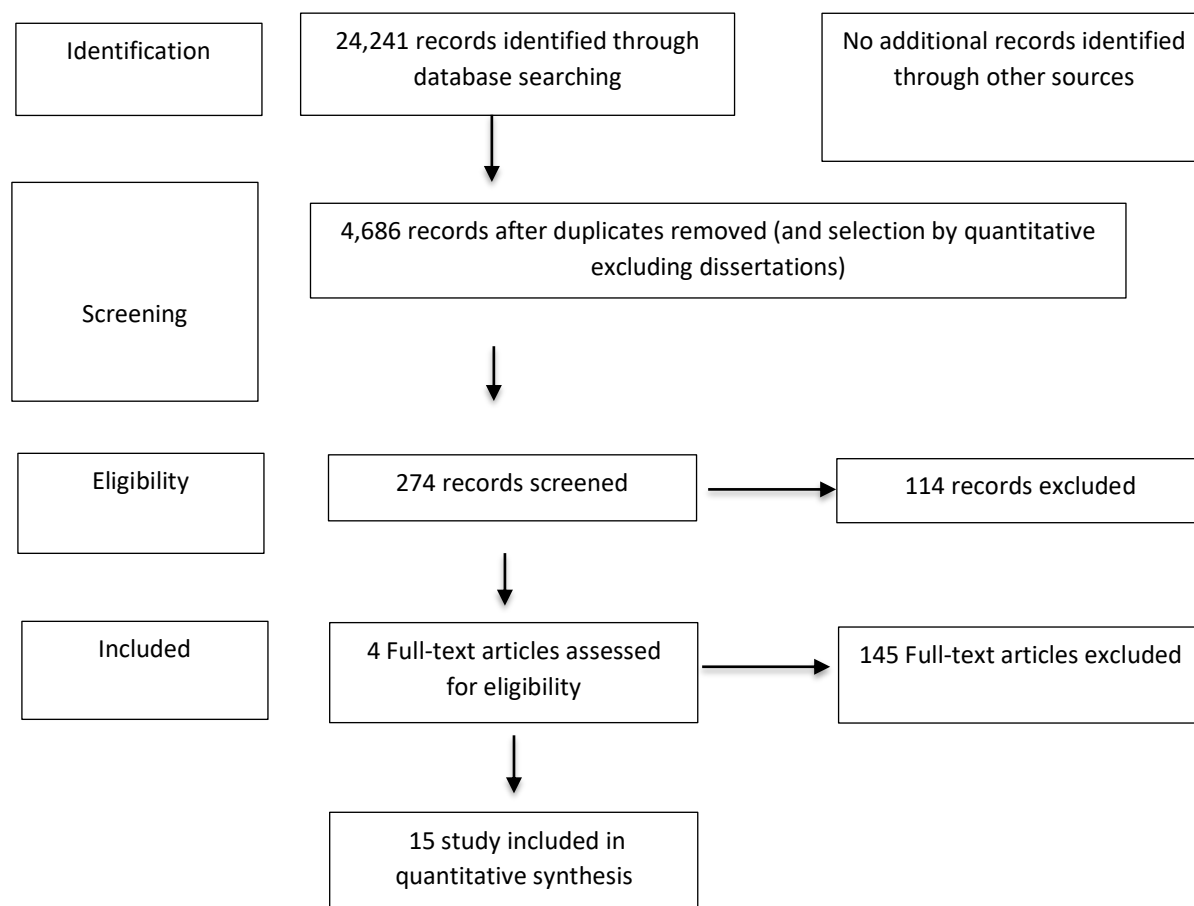
A narrative review of the findings is presented as follows: Table 6 summarises the 15 studies which were identified as investigating coping in caregivers of a child with either a physical, non-physical or complex need. The range of conditions varied, so they were grouped into categories of caregivers of children experiencing conditions with broadly similar attributes. Studies on caregiver coping in children with Learning Disabilities or Intellectual Disabilities were grouped together (Al-Yagon, 2011; McConkey *et al.* 2008; Mirsaleh *et al.*, 2011) as were those which studied caregivers of children with Autism or Down Syndrome (Dabrowska & Pisula, 2010; Pisula & Kossakowska 2010; Rodrigue *et al.*, 1990). A further group included studies with caregivers of children with physical conditions included preterm babies (Madu & Roos, 2006), cancer (Barrera *et al.*, 2004; Murphy *et al.*, 2008) and caregivers of physically challenged children (Hussain & Juyal, 2007). There was one study which did not define the condition type beyond “disabilities” so this study was reviewed individually (Paster *et al.*, 2009). The final grouping studied caregivers of children with complex needs or combined both physical and non-physical conditions (van den Borne *et al.* 1999; Wang *et al.*, 2011). See glossary in appendix 8.

TABLE 6 Summary of key aspects of coping studies

Author	Condition	Group studied	N	Group split of the child's condition	Age range of child in years
Al-Yagon, 2011	Learning Difficulties	Fathers	205	107 Learning Difficulties, 98 Control	8 to 10
Barrera et al. (2004)	Cancer	Mothers	91	69 Cancer, 22 Acute	Mean between 6.25 & 7
Dabrowska & Pisula (2010)	Autism/Down syndrome	Mothers Fathers	162	51 Autism, 54 Down Syndrome. 56 Control Group	2 to 8
Hussain & Juyal, 2007	Physically Challenged	Parents	60	30 Physically Challenged 30 Control	7 to 12
Madu & Roos (2006)	Preterm babies	Mothers	100	50 Preterm, 50 Control	New-borns
Margalit et al. (1992)	LD, mental retardation, emotional/behavioural	Parents	161	78 Disabled, 83 Control	Mean 11.08, SD 5.78
McConkey et al. 2008	Intellectual Disabilities	Mothers	209	98 Taiwan, 62 N. Ireland, 49 Jordan	5 to 18
Mirsaleh et al. (2011)	Intellectual Difficulties	Mothers	248	124 Intellectual Difficulties/124 Control	6 to 13
Murphy et al. (2008)	Cancer	Mothers Fathers	60	20 Fathers, 20 Mothers, 20 Control fathers	18 months to 18 years
Paster et al. (2009)	Disabilities	Parents	112	50 disabilities, 62 Control	6 to 18
Pisula & Kossakowska (2010)	Autism	Mothers Fathers	110	52 Autism, 58 Control	3 to 7
Rodrigue et al. (1990)	Autism/ Down Syndrome	Mothers	60	20 Autism, 20 Down Syndrome, 20 control	control mean 3.8, autistic 10.71, DS 11.93
Solem et al. (2011)	Behavioural problems	Families	192	64 Behavioural, 128 Control	6 to 13
van den Borne et al. (1999)	Prader-Willi, Angelmans	Parents	77	46 Prader-Willi, 31 Angelman	0 to 12
Wang et al. (2011)	Developmental Disabilities	Mothers Fathers	340	137 Autism, 135 Mental Retardation, 44 Physical Disabilities, 52 other Development Disorders	Mean 11 SD 4.17

The systematic review process identified 15 studies on coping from the 24,241 records screened from this category. A summary of the process taken to streamline the coping studies is shown in figure 1.

FIGURE 1 Screening process for selection of coping studies



2.5.2 Coping in Non-Physical Conditions

Of the 15 studies identified on coping, eight focused on non-physical conditions. In three papers, the focus was on Autistic spectrum disorder, Down Syndrome or a combination of these conditions (Dabrowska & Pisula, 2010; Pisula & Kossakowska, 2010; Rodrigue *et al.*, 1990). There were three studies on learning or intellectual disability (Al-Yagon, 2011; McConkey *et al.* 2008; Mirsaleh *et al.* 2011) and one study focused on behavioural problems (Solem *et al.*, 2011). The remaining study used the term “disabled” with the conditions indicated as non-physical (Margalit *et al.* 1992).

The next section will review the studies identified as investigating non-physical conditions and describe them by condition type, giving details of aims, participants, results and strengths and limitations of the study.

2.5.2.1 Autistic Spectrum and Down syndrome

2.5.2.1.1 Aims

There were three studies in this subset of Non-Physical conditions. Two studies compared Autism, Down Syndrome and a control group of caregivers of typically developed children (Dabrowska & Pisula, 2010; Rodrigue, Morgan & Geffken, 1990). Dabrowska and Pisula (2010) examined parenting stress and coping styles in parents of children with autism or Down Syndrome compared to a typically developed control group. Rodrigue *et al.* (1990) examined the impact of an autistic child on the psychosocial functioning of mothers, whilst controlling for confounding factors including marital adjustment, family cohesion, finances and burden. In the third study in this category, Pisula and Kossakowska (2010) compared Sense of Coherence (SOC) and coping differences between the parents of autistic children, mothers of children with Down Syndrome and a typically developed control group.

2.5.2.1.2 Participants

Pisula and Kossakowska (2010) participants were a Polish sample of 26 male and 26 female caregivers of children with autism aged between 3 and 7 who were compared to a typically developed control of 29 caregivers of both genders. Screening was conducted on the experimental group to ensure the children were not experiencing co-morbidities and that no disabilities were present in the control group. Although “number of siblings” was included as part of the demographics, it was not considered in the analysis. The study did not consider other family members with similar or different conditions.

The sample in Dabrowska and Pisula (2010) study comprised of parents of children with either Down Syndrome (n=54), Autism (n=51) or typically developed children (n=57). The children were aged between 2 and 6 years old, and were all in two parent families. Potential co-morbidities were not considered. Although information was collected on the presence and number of siblings, this was not included in the analysis.

Rodrigue *et al.* (1990) had the smallest sample with 20 mothers in each group of children of Down Syndrome (mean age=11.93), Autism (mean=10.71) or a typically developed control (mean age=3.80). Study and control group were matched utilising the Vineland Adaptive Behavior Scale (VABS) composite age equivalent scores. Rodrigue *et al.* (1990) did established that the target child was the only family member with a condition.

2.5.2.1.3 Results

Pisula and Kossakowska (2010) reported differences between the autism group and the control in escape-avoidance coping. Parents of children with autism used escape avoidance more than parents of typically developed children. The WOC coping factors of Seeking Social Support and Self-controlling were identified in the autism and control groups as being correlates of total SOC. In the autism group, *Accepting Responsibility* was indicated as having a negative correlation with total SOC and *Distancing* also correlated with total SOC.

Rodrigue *et al.* (1990) used a revised WOC measure and indicated mothers of autistic children reported more frequent use of *Information Seeking*, *Wish Fulfilling Fantasy* and *Self-Blame*, when compared to the typically developed control group. Mothers of children with autism and Down Syndrome reported more frequent use of self-blame when compared to the typically developed group.

The Coping Inventory for Stressful Situations (CISS), was utilised in the study by Dabrowska and Pusila (2010), so results are not directly comparable with the other two studies in this sub-section of Non-Physical conditions. The CISS generates three categories of coping: Emotion, Task and Avoidance oriented coping. A sub component of Avoidance, *social diversion*, was found to be most commonly used by the caregivers of children with autism. When coping was investigated as a predictor of stress, parents of children with autism and Down Syndrome reported higher use of emotion-oriented coping. Task-oriented coping was a predictor of stress in the sample of parents of typically developed children. Dabrowska and Pisula (2010) hypothesised and confirmed that stress would be higher in autism and different for coping when compared to both the

Down Syndrome and the typically developed control group. Emotion focused and avoidance coping were proposed as predictors of parental stress.

2.5.2.1.4 Strengths and limitations

These three studies focused on non-physical conditions. Pisula and Kossakowska (2010) screened family members to ensure it was only the target child who had a condition. Rodrigue *et al.* (1990) matched the Down Syndrome group and the control group with comparative demographics, but neither Rodrigue *et al.* (1990) nor Dabrowska and Pisula (2010) referred to any potential co-morbidities in their study. This lack of consideration of possible overlapping conditions is typical of the literature identified for the systematic review. All three studies utilised a control group, Rodrigue *et al.* (2010) adopted the robust approach of investigating coping in caregivers of children with autism by comparing this group with another condition, Down Syndrome, as well as a control group of caregivers of typically developed children. It was a strength that a control group was included, although none of these studies took severity or additional care requirements the caregiver may have had into consideration.

In regards to other potential mediating factors, Rodrigue *et al.* (1990) incorporated measures of family adaptability, impact on the family and marital adjustment as part of the understanding of the mother's psychological adjustment, so the measures chosen were appropriate and relevant in regards environmental issues. Dabrowska and Pisula (2010) conducted a comprehensive comparison between all the groups and explored gender differences across some environmental factors. Pisula and Kossakowska (2010) did not use a specific conceptual model or underlying concept and purely investigated SOC and Coping in parents of autistic children. Severity of condition was overlooked although complexity of condition was screened out.

This basic approach towards overlooking environmental factors, potential mediators or underlying concept or theory which may impact on coping is typical

in the literature. These are established, predominant measures with basic categories generated which don't consider factors such as the severity of the child's condition or if they are possibly caring for other children with additional care requirements.

Rodrigue *et al.* (1990) examined the psychosocial functioning of mothers of children with autism from an individual, dyadic, familial, extra familial and community level. A wide range of measures was utilised which addressed the interactions between the mother and multiple contact intersections. The coping measure utilised was a revised version of the WOC which generated new categories through factor analysis. The difficulty with this approach to coping is that comparison with other studies becomes problematic as factor structures could be sample specific.

Analysis of these first three studies highlighted an inconsistent approach towards many variables. The inconsistencies including approach towards coping measures used, environmental concerns and the complexity or severity of the child's condition.

2.5.2.2 Intellectual difficulties

2.5.2.2.1 Aims

There were three studies identified which investigated coping in carers of children with intellectual difficulties (McConkey, Truesdale-Kennedy, Chang, Jarrah & Shukric, 2008; intellectual disability (Mirsaleh, Rezai, Khabaz, Ardekani & Abdi, 2011) and learning disability (Al-Yagon, 2011).

McConkey *et al.* (2008) investigated maternal well-being through the indicators of family functioning, mental health and child-related stresses. Cultural differences in mothers of children with intellectual difficulties were explored. Variables which may moderate or have a negative impact on the mothers' wellbeing and how mothers' coping strategies may be related to available support from the family were also investigated in McConkey *et al.*'s. (2008) study.

The study by Mirsaleh *et al.* (2011) focused on Iranian mothers and investigated personality dimensions, religiosity and coping strategies as predictors of health status. Coping strategies were investigated as a predictor of mental health. The study hypothesised mothers of children with intellectual disabilities would use more problem-focused coping than a control group.

Al-Yagon (2011) tested if fathers coping resources would differ between the learning disabilities group and a typically developed control group. It was hypothesised that the child's attachment style and child's sense of coherence (CSOC) would mediate the relationship between fathers coping resources and children's well-adjusted functioning. These relationships were investigated by examining the contribution of vulnerability and protection as indicated by the child's use of attachment and CSOC and the fathers' coping resources in response to the use of these strategies.

2.5.2.2.2 Participants

Mirsaleh *et al.* (2011) studied 124 Iranian mothers of children classed as intellectually disabled (ID). Selection was conducted by accessing the records of special schools IQ test results, randomly selecting the children and then approaching the mothers. Children with an IQ between 25 and 50 were included, but specific conditions or co-morbidities were not reported. It was acknowledged that the other family members were not checked for ID or any other condition. The ID group compared with a control group of 124 mothers of children without IDs. Both groups were married Muslims with children aged between 6 and 13 years old.

McConkey *et al.* (2008) conducted a cultural comparison of mothers from Taiwan (n=98), Northern Ireland (n=62) and Jordan (n=49) which included coping strategies as part of the study on predictors of general health. The condition explored was classed as IDs and this term was established by the child's attendance at a specialist school. It was stated that across all three samples the conditions included Down Syndrome, autistic spectrum disorders and additional impairments such as epilepsy, but the range or severity of needs were not explicitly investigated in this study.

Al-Yagon (2011) investigated 107 fathers of children with LDs compared to 98 fathers of children with typical development aged between 8 and 12 years old without any health condition. The children in the experimental group were all diagnosed with LD, however it was not stated if the children had any co-morbidities. There was no mention of family members of the LD group being screened for any condition.

2.5.2.2.3 Results

The WOC was utilised in Mirsaleh *et al.*'s (2011) study and the eight subscales were merged into the emotion focused and problem focused coping constructs. When overall coping strategy means were compared between the ID group and the control, no significant differences were found. Regression analysis indicated coping was not a significant predictor of general health.

McConkey *et al.* (2008) also combined the WOC scores into the emotion and problem focused categories. The Irish sample had lower mean scores for problem focused coping than the Taiwanese or Jordanian samples. The Irish sample was also lower on emotion focused coping; Jordanian and Taiwanese mothers were more likely to use emotion focused coping. This was evident particularly when children had more behavioural problems. The use of the coping strategy "problem solving" was a significant factor when mothers were better educated and their children were reported as having fewer behavioural problems. Mother's wellbeing was not impacted by the use of coping strategies.

Al-Yagon (2011) used Moo's Coping Scale (1982) to assess coping styles in parents of children with LD's. This questionnaire generates categories of avoidant and active coping factors. Fathers of children with LD reported a higher level of avoidant coping compared to fathers of children with typical development.

2.5.2.2.4 Strengths and Limitations

These three studies used samples of children with non-physical conditions of ID, however it is not always clear if physical conditions were also present in the target groups. The study by Mirsaleh *et al.* (2011) was based purely on one pre-existing IQ test, with no consideration of type, severity or complexity of the condition. Al-Yagon's (2011) study used the term LD, however, selection was based on attendance of a special school, so it would be reasonable to assume that LD may not be the only condition these children were experiencing, although the behavioural aspects of the condition were tested through the Child Behaviour Check List (CBCL). McConkey *et al.*'s study (2008) included a sample of caregivers of children with a range of conditions which were never quantified for analysis and included both developmental and physical conditions. Pessimism and self-sufficiency in relation to the child's condition were considered and although some levels of complexity of the child's condition were addressed, other factors, such as other child caring responsibilities the caregiver may have were not addressed.

Both Mirsaleh *et al.* (2011) and Al-Yagon (2011) included a control group within their studies: McConkey *et al.* (2008) investigated cultural differences in relation to the ID without control group comparison. The difficulty is that differences in coping based on location may have no bearing on the ID. Variance could be attributed purely to cultural differences, rather than the presence of an ID, in respect of coping strategy utilisation. Including a control group without disabilities would have provided stronger methodology.

Mirsaleh *et al.* (2011) utilised measures of personality, religious tendencies and coping strategies as predictors of general health in Iranian mothers. Although measures used were culturally relevant, variable selection was atheoretical. In the studies by Mirsaleh *et al.* (2011) and McConkey *et al.* (2008) the WOC was only utilised in terms of the dichotomous rating of emotion and problem focused coping, neglecting differences across other subscales. Including the additional factors which the WOC can generate may have added a deeper understanding of the coping process. The study by McConkey *et al.* (2008) aimed at the

understanding of the impact of multiple variables such as family functioning, health, support, resources and stress as well as coping. These are all sound factors, utilising reliable and valid measures, which could help build up a strong picture of cultural impact, for that reason it followed a comprehensive approach. More clarification of the differences in complexity, to ascertain the severity and specific type or nature of the condition would have added value to comparison.

Al-Yagon (2011) took a very different approach compared to the other studies in the review, utilising a strong theoretical model with analysis through Structural Equation Modelling (SEM). The incorporation of the child's perspective also added a dimension of analysis that is not typically evident within the literature. The child's SOC and attachment style were considered in relation to impact of these factors on the father's coping resources and SOC. The measures complemented each other and indicated that active avoidance and father's SOC may have a relationship which is influenced by the child's SOC or attachment style, depending on the presence of a LD. This approach is useful in highlighting complex associations between a range of several factors rather than simple dyadic associations.

The presence of another child with demands may be highly relevant to coping resources. All three studies examined various levels of impact on resources, health status and family functioning but the exact nature of the condition and environmental issues which may have impacted on these factors were not fully examined. As with the previous studies analysed, there were inconsistent approaches, limited use of control groups, lack of definition of co-morbidities or complexity of condition and very specific comparison of specific groups.

2.5.2.3 Other Non-Physical Conditions

2.5.2.3.1 Aims

There were two studies identified in the review which investigated other non-physical conditions. Margalit, Raviv and Ankonina, (1992) presented a model which indicated SOC levels and family climate variables may differentiate

between parents with and without disabled children. This study proposed parents with a disabled child would differ significantly compared to the control group and would present with lower personal coherence and higher avoidant coping. Avoidant coping was hypothesised to be predicted by the presence of disability when compared to a control group, as well as active coping strategies, SOC and familial aspects.

Solem, Christophersen and Martinussen (2011) investigated Norwegian parents' experiences of stress, social support, parents' SOC and coping strategies between parents of a child with behavioural problems and a control group. Solem et al. (2011) hypothesised parents of children with behavioural problems would report more stress and have lower SOC when compared to a control group. It was also hypothesised that having a child with behavioural problems would predict parenting stress, even when controlling for demographics and age.

2.5.2.3.2. Participants

Both studies incorporated general terms to describe the child's condition. The Margalit *et al.* (1992) study described the children of the caregivers in the experimental group as "disabled" and included Israeli children with learning disabilities, mental retardation and emotional disorders (n=78) compared to a typically developed group (n=83). The study only polled the behavioural aspects of the participants through the CBCL, so severity of condition and type of disability were not fully considered for the participants' children. The average age of the experimental group was reported ($M=11.08$, $SD= 5.78$) but the age of the children in the control group was not stated.

Solem *et al.*, (2011) investigated parents of boys aged 6 to 13 years old with a range of conditions described as "behavioural problems", which included children with ADHD (n=46), Disruptive disorder or "other problems" (n=16) and no diagnosis (n=2). The control group was much larger (n=128) compared to the experimental group (n=64). It was not reported if any other family members had any condition, in either the experimental or control group. Although family

support levels were considered, severity and complexity of condition were not accounted for in this study.

2.5.2.3.3 Results

In Solem *et al.*'s (2011) study it was indicated that there were no differences in coping strategies between groups. The coping measure used was the Coping Orientation to Problems Experienced Scale (COPE) which has well established psychometric properties and good internal consistency (Carver *et al.* 1989). The findings indicated that the prevalence of risk factors such as less education, less support and being single made the clinical group more vulnerable when compared to the typically developed group.

Margalit *et al.* (1992) reported in their study that, in comparison to the control, parents with disabled children presented lower SOC and increased use of avoidant coping. Parents who used more avoidant coping used more active coping as a strategy and reported feeling less coherence. The group of parents with disabled children also reported that they placed more emphasis on systematic aspects of their family climate. Families of parents with disabled children in this study were found to be less able to support their family and to foster individual growth.

2.5.2.3.4 Strengths and limitations

Margalit *et al.* (1992) partially addressed complexity by including the CBCL, but this measure is designed to gauge behavioural impact so other aspects of complexity, such as physical or psychological elements of a condition, were not explored. In the study by Solem *et al.* (2011), the CBCL was used as a pre-screen for the clinical group; however, the data were not incorporated in the analysis. Environmental factors were addressed to varying degrees with exploration of the child-rearing environment and social support. Margalit *et al.* (1992) included the Family Environment Scale, which does cover potential environmental influences with three subscales including relationships, personal

growth and system maintenance. Neither study considered the possible impact of another child in the family who may also have a condition. Both studies utilised a control group, although in the study by Solem *et al.* (2011) the control group was significantly larger than the experimental group. Solem *et al.* (2011) reported that the size of the control group was the result of a low response rate (29%) so the intention may have been to have a larger control group.

Margalit *et al.* (1992) explored differences between parents with and without disabled children and how SOC levels and family climate variables differentiated between the two groups. The Family Environment Scale (FES) was utilised for the family climate element. The FES measure provided information on relationships, personal growth and system maintenance but the more recognised QRS could have possibly generated a larger range of potential mediators. Moo's (1982) coping scale does generate generic constructs such as Active and Avoidant coping. This is similar to other measures such as the WOC, with Emotion and Problem-focused constructs; however additional subscales were available but not utilised, which could have increased specificity of the findings.

Solem *et al.* (2011) did not use a specific theoretical model and incorporated a wide range of measures including coping, SOC, social support and family demographics. Choice of measures appears to be atheoretical in this study.

2.5.2.4 Summary of studies on Non-Physical Conditions

A variety of methodological approaches identified across studies which investigated coping, ranging from basic comparison between groups (Hussain & Juyal, 2007; Madu & Roos, 2006; Paster *et al.*, 2009) to fully formed models using MSEM (Al-Yagon, 2011). Participants were from a wide range of locations; Poland, Israel, Northern Ireland, Taiwan, Jordan, Iran, America and Norway. The measures used and results reported were also quite varied in relation to coping. The proposed aims and methodological approaches taken

were diverse and inconsistent, and there were no predominant coping measures used.

The measures used varied from Moos's Coping Scale (1982) (Al-Yagon, 2011; Margalit et al. 1992), COPE (Solem et al., 2011) and the CISS (Dabrowska & Pisula, 2010). There were four studies which employed the WOC but with different aims and variation in nature of samples (Mirsaleh et al., 2011; McConkey et al., 2008; Pisula & Kossakowska, 2010; Rodrigue et al., 1990). Rodrigue et al., (1990) used a modified Ways of Coping Scale which generated different subscales than the traditional WOC. The studies by McConkey (2008) and Mirsaleh (2011) utilised the broad scales of emotion and problem focused and Pisula and Kossakowska (2010) employed all eight subscales. Coping was not always found to be a significant factor within the investigations (Mirsaleh et al., 2011; McConkey et al., 2008; Solem et al., 2011). Self-blame and emotion-oriented coping strategies were found to be utilised by carers of children with non-physical needs compared to a typically developed group in two of the studies (Dabrowska & Pisula, 2010; Rodrigue et al., 1990). The measures used were varied and even when the same coping measurement was utilised in different studies, they were rarely utilised with the same factors. Coping measures utilised within this specific population were inconsistent, which made comparison challenging.

Within the eight studies, three reported avoidance strategies being higher in caregivers of children with non-physical conditions compared to a typically developed control comparison group. (Al-Yagon, 2011; Margalit et al., 1992; Pisula & Kossakowska, 2010). Although the measures used the same term of avoidance as a construct, the items and statements varied between measures, so they were not directly comparable. Both Margalit et al. (1992) and Al-Yagon (2011) utilised the Moos (1982) coping scale; however, Pisula and Kossakowska (2010) utilised the WOC. Because of variability in definitions of complex needs, aims and measures it is almost impossible to compare the findings across studies.

Although having more than one child with a condition may have additional impact on the family and particularly the primary caregiver, this was rarely considered across studies. The complexity of a child's condition, particularly if there are elements of physical, psychological and behavioural demands present, could also impact on parental stress. Multiple demands, complexity and severity have not been adequately addressed within the studies identified in this section of the systematic review. The Pisula and Kossakowska (2010) and Rodrigue et al. (1990) studies screened the families of the typically developed children to confirm there was no diagnosis of disability in the family and the children with autism were confirmed as having no other developmental disorder. These two studies were the exception with the review, as they partially addressed some of the environmental issues which may influence caregivers' coping.

Consideration of the impact of co-morbidities on caregivers coping strategies and how complexity and severity may influence coping strategies was found to be lacking in these eight studies. When this lack of consideration is combined with inconsistencies in regards to aims, types of measures utilised and analysis approach, even within the small group of caregivers of children with non-physical needs, no underlying theme or trend was discernible.

2.5.3 Coping in Physical Conditions

There were four studies which investigated coping in caregivers of children with physical conditions. The conditions covered included cancer (Barrera, D'Agostino, Gibson, Gilbert, Weksberg & Malkin, 2004; Murphy, Flowers, McNamara & Young-Saleme, 2008), preterm babies (Madu & Roos, 2006) and physically challenged children (Hussain & Juyal, 2007).

2.5.3.1 Aims

Barrera *et al.* (2004) compared mothers of children with cancer (MCC) with mothers of children with acute conditions (MCA), examining predictors and mediators of psychological adjustment. The hypothesis was that the MCC group

would have poorer psychological adjustment and employ more emotion focused coping than the MCA group. It was also hypothesised that increased emotion focused coping would be associated with higher rates of depression, anxiety and poorer general mental health.

Murphy *et al.* (2008) aimed at describing fathers' experiences and how paternal adjustment affected child adjustment. It was hypothesised that fathers of children with cancer would spend more time with their children and would have more stress, compared to the control group. The study suggested that use of problem focused strategies would have a positive effect on distress in all parent groups.

The level of maternal depressive symptoms and ways of coping in mothers of pre-term infants compared to a control group of mothers of full term babies was investigated by Madu and Roos (2006). It was proposed that the mothers of pre-term babies would have higher depression, particularly within the first week when compared to controls. Coping strategies were hypothesised to be different between groups.

Hussain and Juyal (2007) examined levels of stress of parents with disabled children and the ways of coping with stress adopted by them. They hypothesised differences in both stress and coping between the parents of physically challenged parents compared to parents of "normal" children.

2.5.3.2 Participants

In Barrera *et al.*'s (2004) study, the sample was comprised of 69 mothers in the MCC group diagnosed with cancer in the previous 3 months. There were 22 mothers in the MCA group. The type of cancer was considered, however the severity, stage, type of treatment and overall complexity of the cancer were not considered. The comparison group comprised of parents of children with various ailments such as broken limbs (19%), gastrointestinal infections (31%) and minor surgery such as appendicitis (50%). The caregiver's children were all aged between 6 and 7 years old.

The participant sample in the Murphy *et al.* (2008) study consisted of 60 parents: 20 mothers and 20 fathers of children with cancer and 20 parents of healthy children. The age range of the children was between 18 months to 18 years. The children with cancer were at least 4 months' post-diagnosis. Stage of illness, treatment regimens and other potential additional family demands of the parents of children with cancer were not referred to. Illness duration was the only severity factor in relation to the child's condition which was included.

Hussain and Juyal's (2007) study comprised of 60 parents (gender not provided) of male children, 30 in the experimental group and 30 in the control group. The only inclusion criteria listed was attendance in a special school in Delhi. There was no information on type, severity or complexity of the condition beyond that of "physically challenged".

Participants were from a Pretoria academic hospital in the study by Madu and Roos (2006). There were 50 mothers of babies born before 37 weeks with low birth-weight. The control group comprised of mothers of new-born full-term babies.

2.5.3.3 Results

The MCC group reported more symptoms of depression, greater use of emotion-focused coping strategies and more social support use in the study by Barrera *et al* (2004). The higher use of emotion-focused coping was suggested as indicating that mothers of children with cancer had a unique challenge in managing their own emotional response compared to the MCA group.

Murphy *et al* (2008) also utilised the general categories of emotion and problem focused from the WOC. Coping style was different in each of the groups. Mothers who engaged in more problem-focused solving reported less depression, anxiety and overall distress. For fathers in the group of children

with cancer, coping was associated with the number of hours' fathers worked and the duration of the child's illness.

Hussain and Juyal (2007) used two measures for coping, the Stress Appraisal Measure (SAM) and the WOC. The SAM consists of seven subscales and three general scales of primary and secondary appraisal and overall "stressfulness". The score for coping appeared to be an amalgamation of all the coping statement answers from the WOC which generated one overall score for "coping". The mean for the "physically challenged" group was 93.4 compared to 149.3 for the "normal" group. The authors concluded that results "clearly indicated that the stress coping strategies of parents of normal children were certainly better".

Madu and Roos (2006) utilised the eight subscales of the WOC. The coping measure of *Seeking Social Support* was found to be significantly associated with depression in mothers of pre-term babies and accounted for 17.4% of the variance on depression scores. This contrasted with the mothers of full-term babies. The significant coping measure for this group which contributed to depression was Accepting Responsibility. This accounted for 8.4% of the depression scores variance. The internal consistency of the WOC in this study was low. The Cronbach's alpha ranged between 0.46 and 0.64 for six of the scales utilised in this study. The Cronbach's alpha coefficient for Accepting Responsibility and Distancing were very low at 0.34 and 0.36 respectively.

2.5.3.4 Strengths and Limitations

Barrera *et al.* (2004) investigated the stress of a cancer diagnosis with that of having a child in the hospital with an acute condition. This was to establish if the MCC were reacting to a stressful situation or if the cancer diagnosis created unique adjustment challenges. The conditions included parents of children with routine conditions such as broken limb or gastrointestinal illness. The severity and complexity of the conditions in the acute group were not stated beyond the condition description. The difference between the conditions in the acute group could vary with regards to the stress parents are experiencing, for example, a

broken limb is a routine procedure which may not cause a parent much stress compared to a gastrointestinal illness where the outcome may be unknown.

Murphy *et al.* (2008) took a comprehensive approach towards understanding adjustment of fathers of children with cancer by comparing the fathers to mothers of children with cancer as well as a healthy control group of fathers. There were 20 participants in each of the three groups, with a broad age range of children between 18 months to 18 years and varying levels of need. The CBCL was utilised for the impact of behavioural element of the illness. Complexity of the condition and any co-morbidities were not reported. Coping was only explored in terms of emotion and problem focused categories, although it would be useful to investigate the other subscales of WOC.

Madu and Roos (2006) compared two groups of mothers with new born babies in their study. The criteria for inclusion in the pre-term group were babies weight and if they were born 3 or more weeks prematurely. It was hypothesised that mothers of pre-term babies would experience more depression than mothers of full term babies. High levels of depression were found in both groups, although seeking social support was indicated as significant predictor of depression in the pre-term group and accepting responsibility was a significant predictor of depression for the full-term group, although Accepting Responsibility had a low reliability coefficient (Cronbach Alpha = 0.34). Selection of variables was atheoretical and severity and complexity of condition were not considered. Possible extraneous variables, such as other family stresses the mothers may be experiencing, or pre-existing depression were also not considered.

Hussain and Juyal (2007) included a healthy control group in their study; however, the theoretical approach, participant characteristics and methodology were not robust. The study used a general definition of the condition “physically challenged” therefore severity of condition and environmental factors have not been investigated in relation to coping. It is important to mention that the WOC is not designed to generate one overall score and arbitrary use of a global score might have compromised the findings.

2.5.4 Undefined Conditions

There was one study which did not specifically fit into either Physical or Non-Physical conditions as the condition was described as “disabled” with no indication of what this involved (Paster, Brandwein & Walsh, 2009).

2.5.4.1 Aims

The purpose of the Paster et al, (2009) study was to compare parents of children with a disability compared to a control. It was hypothesised that coping strategies would be different between groups. It was proposed that parents of children with disabilities would use the WOC coping strategies of Seeking Social Support and Planful Problem Solving more often than the control group parents.

2.5.4.2 Participants

There were 50 parents of children with disabilities and 62 parents in the control group. The children were aged between 6 and 18 years old. Complexity and severity of the child’s condition and possible environmental stressors were not investigated as mediators of coping in this study.

2.5.4.3 Results

Seeking Social Support was significantly higher in the disabled group than the healthy control group. The two groups did not differ in *Escape Avoidance*.

2.5.4.4 Strengths and Limitations

A strength of Paster et al.’s study was the use of a control group however, the only measure used was the WOC so findings were limited. The lack of definition of the “disabled” group meant that it was difficult to know what the control group were being compared to. There was no consideration of severity, complexity or basic type of condition the caregivers might be caring for. Selection of variables was also atheoretical so the findings are quite limited in regards what has been gained by conducting this study.

2.5.5 Coping and Complex or combined conditions

2.5.5.1 Aims

There were two studies which incorporated physical and non-physical conditions. (Wang, Michaels & Day, 2011; van den Borne, van Hooren, van Gestel, Rienmeijer, Fryns & Curfs, 1999). Wang *et al* (2011) aimed to increase the knowledge of Chinese families of children with autism and other developmental disorders. The study explored perceived stresses, types of coping styles and differences between mothers and fathers strategies. The study also enquired if there were differences in stress and coping in relation to disability type.

The study by Van den Borne *et al.* (1999) hypothesised characteristics of the child's condition were associated with parental psychosocial problems and coping strategies. The conceptual model assumed that uncertainty, negative feelings (fear and depression), loss of control and threats to self-esteem are the four most important psychosocial problems experienced when there is a health threat. Coping strategies were expected to be called upon in an effort to prevent or reduce these problems. The coping strategies utilised for this model were "cognitive and behavioural avoidance", "active problem solving" and "seeking social support".

2.5.5.2 Participants

Wang *et al.* (2011) had a large and diverse sample in their study. The 340 participants included 216 mothers, 124 fathers, 9 grandmothers and 13 grandfathers. There were 258 male and 108 female children. There were 137 with autism, 135 with mental retardation, 52 with other developmental disorders and 44 with physical disabilities. Some aspects of the child's condition severity were addressed through subsets within the measures utilised. Perceptions of limitations in the child's physical disabilities, self-help skills and child's characteristics were investigated as mediators of coping. However, severity and complexity of condition were not investigated as potential mediators of coping.

Van den Borne *et al.* (1999) used a sample of 46 parents of children with Prader-Willi syndrome (mean age= 7.3 years old) and 31 parents of children with Angelman syndrome (mean age=7.2 years old). These conditions have different presentations although both include physical, developmental and behavioural disabilities.

Prader-Willi syndrome is characterised by severe neonatal hypotonia, feeding difficulties, delayed development and in the first few months of life, severe muscle hypotonia and failure to thrive. It is also stated that the condition includes a psychological and behavioural phenotype including insatiable appetite, outbursts of rage and difficulty dealing with changes to routine. Skin picking and abnormal sleeping patterns are also associated with this condition. Angelman syndrome is characterised by severe or profound learning difficulties, lack of speech development, delayed motor development, inappropriate bouts of laughter, and an ataxic gait. This condition often includes microcephaly and epileptic seizures. Severity and complexity were not considered as potential mediators of coping (van den Borne *et al.*, 1999).

In regards to environmental considerations of the participants, there were some inconsistencies. Some of the children were not living at home, 5 of the children with Prader-Willi syndrome were living in an institution or in sheltered homes. In the Angelman group, 4 children lived in an institution and 3 children combined living in an institution and living at home. These differences were not accounted for in the analysis. Neither Wang *et al.* (2011) nor van den Borne *et al.* (1999) included a control group in their study.

2.5.5.3 Results

Wang *et al.* (2011) used the 15 subscales of the COPE Inventory highlighting nine factors which were more commonly used by caregivers of children with developmental and physical needs and disorders: Use of Instrumental Social Support, Active Coping, Denial, Behavioural Disengagement, Restraint, Substance Use, Acceptance, Suppression of Competing Activities and

Planning. Denial was higher in caregivers of children with mental retardation than caregivers of children with autism. Behavioural Disengagement was also less likely to be used as a coping strategy in caregivers of children with autism when compared to both the mental retardation group and the other developmental disorders group. Substance Use was lower in caregivers of children with autism when compared to caregivers of children with mental retardation. Planning was used as a coping strategy more for parents of children with autism when compared to caregivers of children with mental retardation.

The study by van den Borne *et al.* (1999) reported that both groups of parents of children with Angelman syndrome and Prader-Willi syndrome had a high need for information, high feelings of loss of control and relatively high feelings of depression. Coping strategies were not found to be different between parents of children with either type of syndrome.

2.5.5.4 Strengths and limitations

Van den Borne *et al.* (1999) investigated coping in parents of children with complex conditions. Although a measure of severity and complexity of the child's condition was included it was not comprehensive. Despite the fact some children from both groups were living in institutions, sheltered housing and combination residential care, there was no consideration of potential environmental differences within the analysis. Psychosocial problems in parents of children with complex needs were explored in terms of uncertainty, depression, fear and self-esteem. The study by van den Borne *et al.* (1999) did increase knowledge on coping in parents of children with these very specific conditions. It would have been useful if a control group of normally developed healthy children had been used or other conditions with less complex needs had been included. This design could have offered viable information regarding how severity of the child's condition could potentially impact on parental coping style.

Wang *et al.*'s (2011) study had many strengths such as the sample size being large with a good mix of participants and conditions. It was the only study identified as part of this review with physical and non-physical categories which were also investigated categorically in relation to coping. The findings suggested parents of children with autism were less likely to use denial and behavioural disengagement and substance use as coping strategies compared to other conditions. It was also suggested that parents of children with autism used more planning when compared to parents of children with mental retardation. However, despite this progressive approach, the nature of the condition categorisation utilised in this study was problematic. Severity and complexity of condition were not considered specifically with categories including "other developmental disorders" and "physical disabilities" which were not explained. These categories could include mild or severe symptoms which may have a bearing on how parents utilise coping strategies.

2.5.6 Summary of Studies on coping strategies.

Because of the diversity across studies in terms of aims, populations and measures used, there was no pattern discerned in relation to coping strategies used by caregivers of children with any complex need. Some studies focused on one condition compared to a control group (Al-Yagon, 2011; Hussain & Juyal, 2007; Margalit *et al.*, 1992; Mirsaleh *et al.*, 2011; Paster *et al.*, 2009; Pisula & Kossakowska, 2010; Solem *et al.*, 2011) or another condition. (Dabrowska & Pisula, 2010; Rodrigue *et al.*, 1990; Wang *et al.*, 2011). Only one study was found that included physical and non-physical conditions as separate categories (Wang *et al.*, 2011). There was no consistency, underlying pattern or approach detected within the studies and no study specifically investigated complex needs. Severity and complexity of the condition and environmental concerns were not adequately addressed in the studies identified for this review.

Selection of coping measures investigated appeared for the most part atheoretical and quite arbitrary in regards to underlying reason with few

exceptions. Al-Yagon's (2011) study included measures examining relationships between each father's coping resources and his child's socioemotional adjustment. The measures used were appropriate for the father and the children and were robust for the elements being explored. In the Wang et al. (2011) study, the combination of the COPE and QRS were good measures to use in investigating stresses and coping, which was the specific purpose of the study. These two studies were not typical within the literature and in sharp contrast to other studies such as Paster et al. (2009) and Hussain and Juyal (2007) and their approach towards classification of illness and the way measurements were utilised. Paster et al. (2009) only employed the WOC and omitted any explanation as to why this coping measure was chosen and lacked a definition of what was meant by the term "disability". When there is only one construct being tested, the measure being utilised is vitally important. The approach taken by Hussain and Juyal (2007) which amalgamated all the scores for the WOC statements into one score was an example of inappropriate use of measures. For the majority of the studies in the review, the underlying explanation of why a particular coping tool was utilised was lacking.

Avoidant coping was the most commonly reported coping strategy for caregivers of children with either a non-physical or physical condition within the studies in the review. Coping was found to be non-significant in many of the studies reviewed. The studies often incorporated other measures and constructs such as SOC and depression. These additional constructs were investigated as additional factors or predictors rather than potential mediators of coping in caregivers of children with additional needs.

Factors such as depression (Barrera *et al.*, 2004; Madu & Roos, 2006; van den Borne *et al.*, 1999) and SOC (Al-Yagon, 2011; Margalit *et al.*, 1992; Pisula & Kossakowska, 2010; Solem *et al.* 2011) were often included in studies more often than other constructs such as psychological adjustment (Barrera *et al.*, 2004), psychosocial problems (van den Borne *et al.*, 1999) or stress (Solem *et al.*, 2011). The constructs included in the studies were not found to be significantly associated with coping. Sample sizes also varied significantly

across all studies as did comparison groups and criteria. Overall there was no consistency across the studies identified by the systematic review in relation to aims, participants, consideration of environmental factors, measures used, diversity of conditions investigated or underlying theory or model. No studies which considered potential mediators of coping were found.

2.5.6.1 Coping approach in relation to this study

This present study explores mediators of coping in caregivers of children with complex needs. The systematic review confirmed that although coping and caregivers of children with a range of additional needs were widely investigated, the approach towards coping was inconsistent and often without an underlying theoretical basis. Although many specific conditions were focused on and compared, complex needs were not investigated within the literature.

This current study aimed to address the gap in the literature by investigating caregivers of children with physical, non-physical or complex needs and by utilising a coping measure which has five specific action-based coping strategies. The severity and complexity of the child's condition and how this impacts on coping in combination with choosing the optimum coping measure which was fit for purpose was viewed as vital for this investigation.

The other key factor of this investigation was to study constructs which may act as mediators for caregivers of children with complex needs when coping strategies are utilised. For the next part of the systematic review, a search was conducted for studies which included coping and any of the mediators chosen for this study: Adult Attachment, Emotion Regulation and Cognitive Fusion.

2.5.7 Potential Mediators of Coping

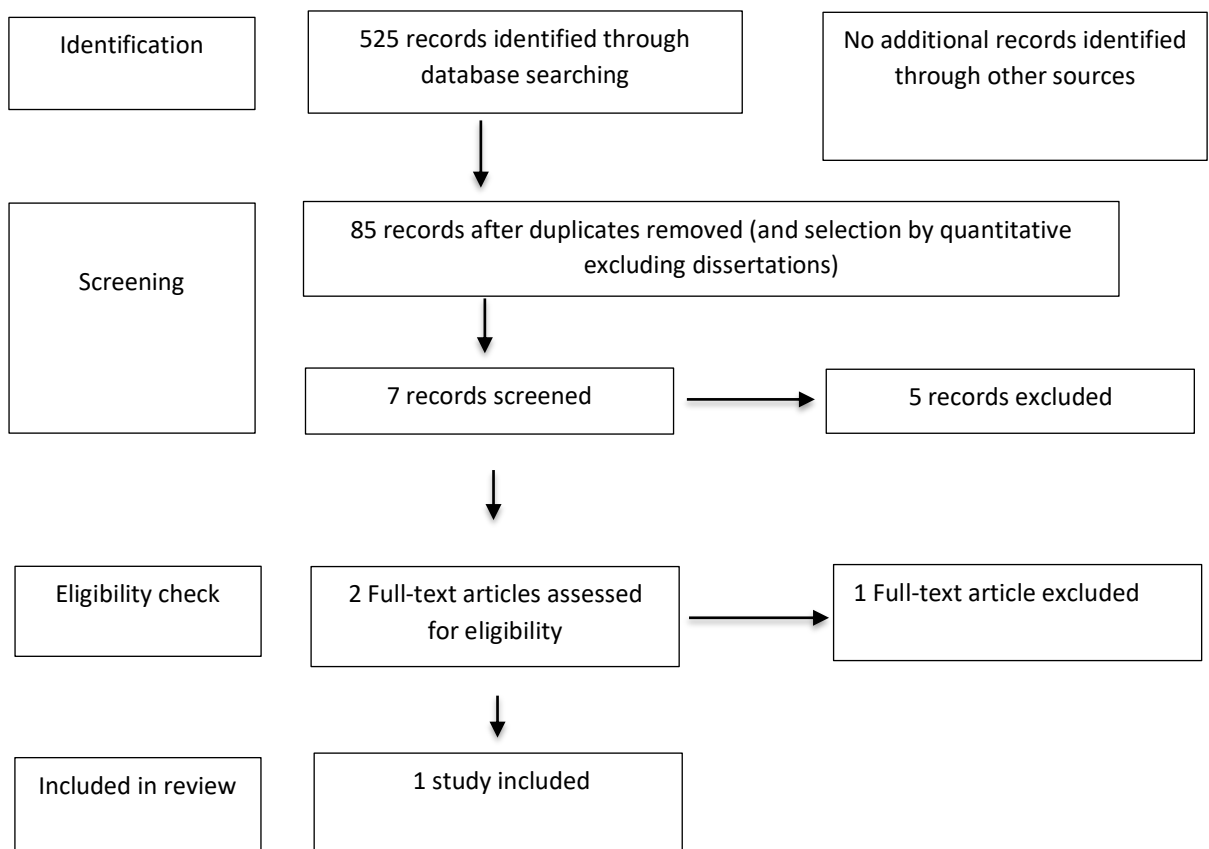
Adult Attachment, Emotion Regulation and Cognitive Fusion were each combined with coping as per the inclusion and exclusion criteria outline in

Section 2.4. Although a thorough search was conducted only one study was identified, in Adult Attachment (Figure 2).

2.5.7.1 Adult Attachment

The section below described a study which met the inclusion criteria of the systematic review and included both coping and adult attachment measures within the investigation (Al-Yagon, 2007).

FIGURE 2 Screening process for selection of Adult Attachment studies



2.5.7.1.1 Aims

Al-Yagon (2007) aimed to examine the role that maternal resources (coping strategies, affect and attachment style) had in moderating learning difficulties on children's socio-emotional and behavioural adjustment. Maternal personal resources (level of avoidant/active coping, negative/positive affect and anxious/avoidant attachment style) were hypothesised to moderate the effect of children's ID on their socio-emotional and behavioural adjustment.

2.5.7.1.2 Participants

There were 110 mother child dyads, 59 children had ID and 51 children were in the typically developed control group. All the children were aged between 8 and 12 years old. The children in the control group were selected by identification of a diagnosis of ID, which was based on IQ scores. Due to confidentiality constraints, characteristics of individual children were not reported. This meant severity of condition was not considered as a correlate of coping. One element of severity, behavioural difficulties, was measured through the mothers' use of the CBCL. Mothers of children in the control group confirmed no IDs present in the children. Presence of co-morbidities or siblings in the experimental group who may have other conditions and demographic variables, such as education level and income, were not considered in relation to coping.

2.5.7.1.3 Results

It was found that 23% of the variance in children's attachment security scores was explained by the children's group affiliation and by mother's use of "avoidance in close relationships". An additional 4% of the variance was explained by "maternal avoidant attachment" scores. Results indicated a high level of maternal "avoidance in close relationships" was associated with a child's low scores on attachment security in the ID group. Maternal low use of avoidant coping was reported as appearing to protect children with ID from experiencing strong feelings of loneliness. A lower level of maternal avoidance in close relationships with significant others, which was a subset of attachment avoidance, seemed to buffer children in the ID group from experiencing low feelings of hope.

2.5.7.1.4 Strengths and Limitations

This was the only study identified by the systematic review that investigated the association between attachment and coping. The study was based on mothers only and the children were between 8 and 12 years old with limited generalisability capacity of the findings across other age groups. The study focused on IDs, neglecting potential co-morbidities. Severity of the condition was not measured, except for a behavioural element being measured through the CBCL. The measures testing for attachment, affect and coping utilised the

global rating categories for each measure. This meant findings lacked specificity; findings on generic constructs such as Anxious and avoidant attachment style (Experiences in Close Relationship Scale, ECR Measure), avoidant and active coping (Moo's Coping Scale) and externalising and internalising behaviours (CBCL measure) were the dichotomous subscales reported. This global use of measures, in conjunction with the lack of incorporation of severity and complexity, resulted in a lack of in-depth analysis. The study suggests an association between coping and attachment which warrants further investigation. Viewing attachment as a mediator of coping would appear to be a beneficial line of enquiry to increase our understanding of coping in caregivers of children with complex needs.

2.5.8 Emotion Regulation and Cognitive Fusion

As can be seen by figure 3 and 4, there were no studies which combined coping and either Emotion Regulation or Cognitive Fusion in caregivers of children with additional care needs when the inclusion and exclusion criteria as outlined in table 3 were applied.

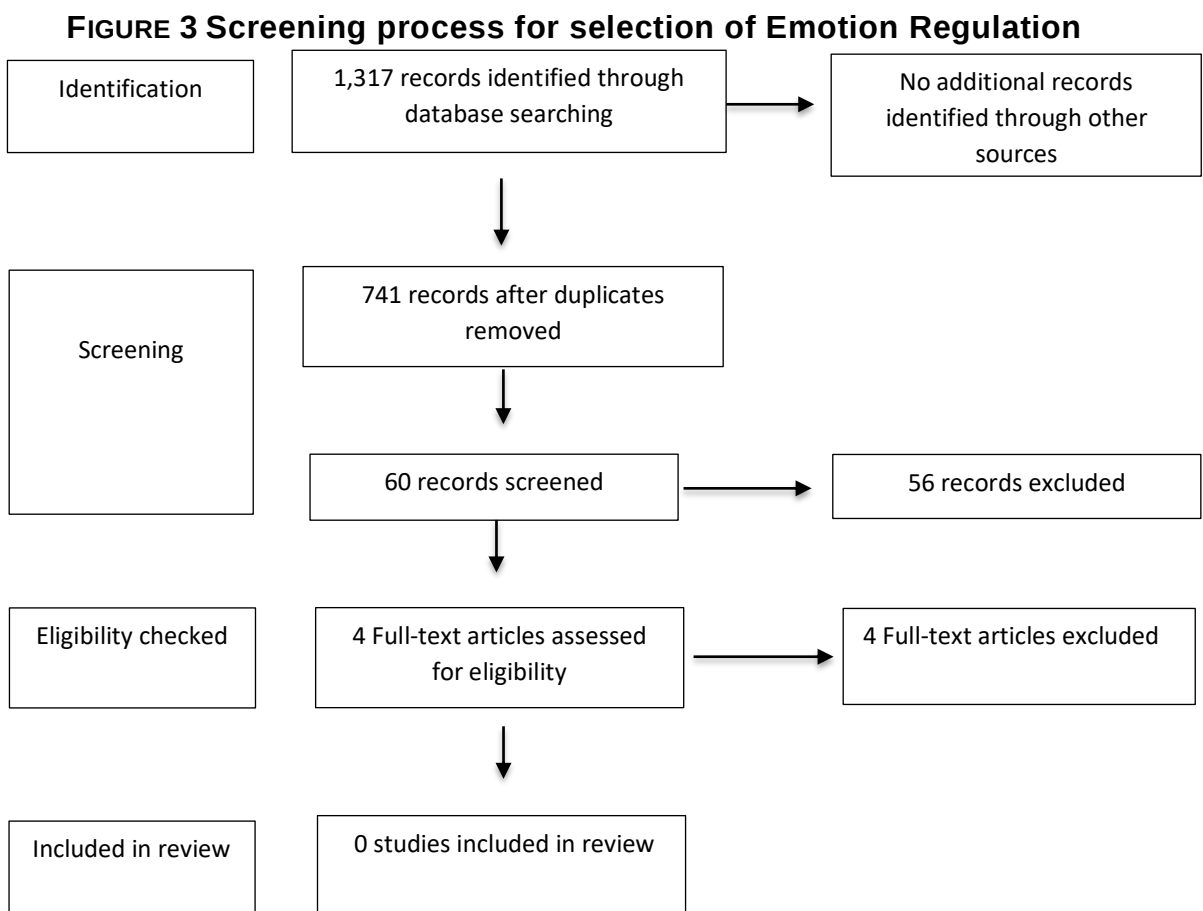
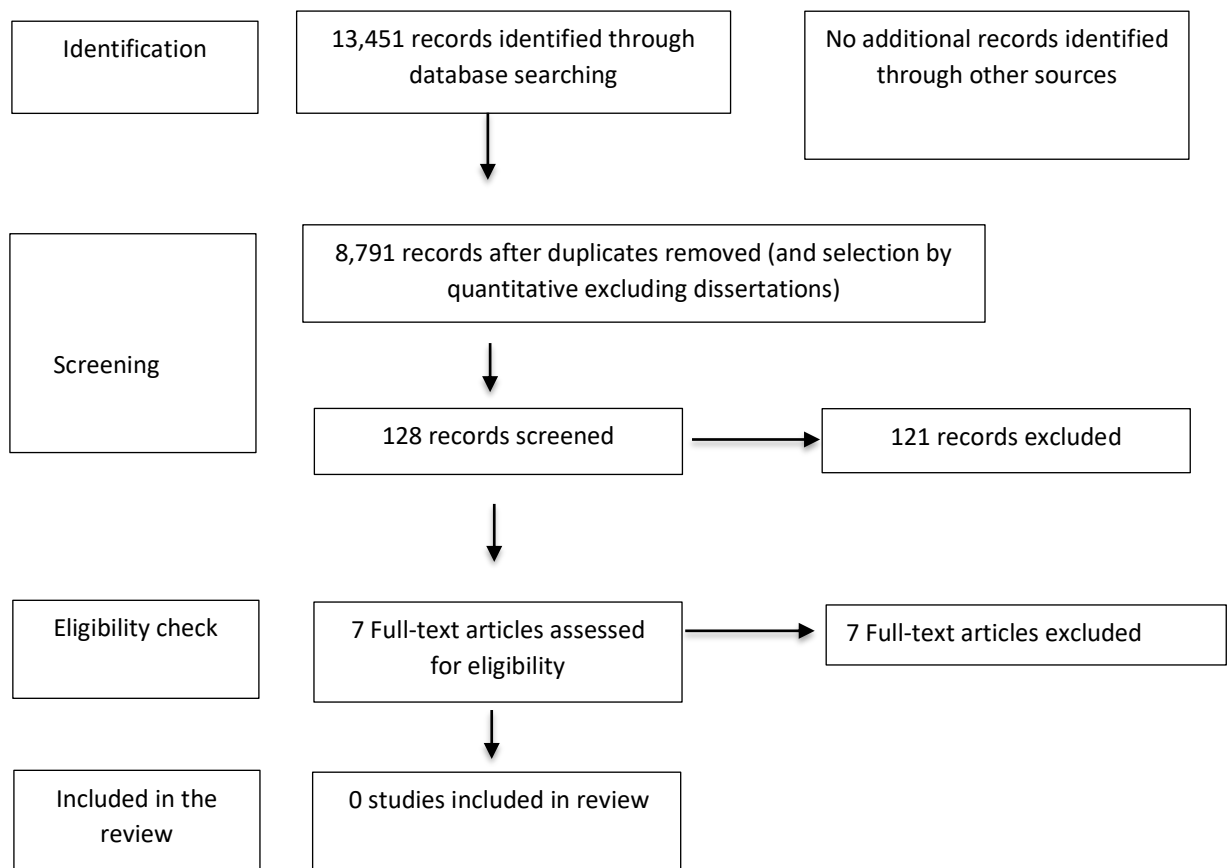


FIGURE 4 Screening process for selection of Cognitive Fusion studies



2.6 Summary of systematic review

This systematic review evaluated studies on coping and studies with potential mediators of coping in caregivers of children with complex needs. There were some studies which examined the relationship between coping and another measure as part of their aims. Pisula and Kossakowska (2010) investigated the relationship between coping and SOC in parents of children with autism. Madu and Roos (2006) investigated correlations between coping and depression in mothers of preterm infants. This approach was not evident in the other studies identified by the review. The majority of the studies reviewed focused on a specific construct and applied measures such as coping, depression, SOC and family resources in order to understand the construct more. These constructs included stress (Dabrowska & Pisula, 2010; Solem et al., 2011; Wang et al.,

2011) Psychological functioning or adjustment (Barrera et al., 2004; Murphy et al., 2008; Rodrigue et al., 1990; van den Borne et al., 1999) General health (Mirsaleh et al., 2011) Maternal wellbeing (McConkey et al., 2008), the child's socio-emotional and behavioural adjustment (Al-Yagon, 2007, 2011) or family interactions and personal growth (Margalit et al., 1992). Coping and other measures were typically utilised side by side such as stress appraisal and WOC (Hussain & Juyal, 2007), but they were not interpreted as mediators. To summarise, there were studies which investigated the relationship between different measures such as coping and SOC, or coping and depression, however no studies were identified which utilised another measure or construct as a mediator of coping.

The systematic review indicated there was no consistency in regards to choice of mediators, if it was considered in the study. In addition to this lack of consistency, reviewing the aims, participants, results and coping measure, approaches revealed a level of diversity which made it difficult to reach concrete conclusions regarding the types and mediators of coping for caregivers. The review of coping studies confirmed complex needs were rarely investigated. Severity was sometimes partially explored through behaviour measures but this was only one factor and was not consistent. Complexity was not found to be investigated in association with coping in any of the studies. Factors such as a child's multiple needs and the presence of siblings with conditions could impact on the coping resources of the caregiver as could severity and complexity of the child's condition.

The systematic review highlighted many flaws in how both coping and caregivers of children with any additional care requirement are investigated. It is generally accepted that caregivers of children with any additional care requirements are under more stress than their counterparts with typically developed healthy children. It therefore seems logical to propose caregivers of children with complex needs may require more robust or different coping strategies to manage the higher demands they may experience.

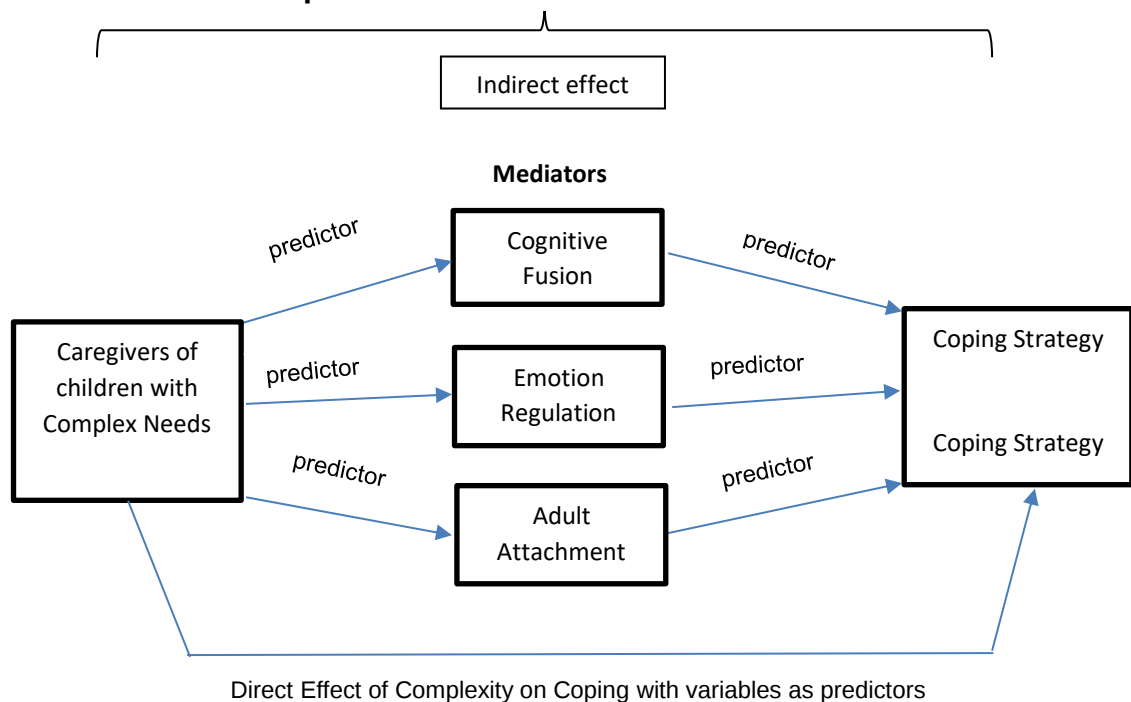
The systematic review established that coping in caregivers of complex needs and potential mediators of coping were not areas of research that have been investigated within the literature. The gaps in the literature established by conducting the systematic review confirmed that this study was worthwhile, as a way of exploring a range of areas not yet considered within the body of work on coping in caregivers of children with additional needs.

3. Conceptual theoretical model

The results highlighted by the systematic review informed the development of a new proposed conceptual model of coping where the coping strategy utilised by caregivers of children with complex needs is potentially mediated by Adult Attachment, Emotion Regulation and Cognitive Fusion. These three variables have distinct attributes, which have the potential to be powerful thoughts, drives and internal emotions, which may influence coping strategy actions taken.

The model (figure 5) suggests that there may be a total effect where Complex Needs is directly linked with the type of coping strategy usage in caregivers of children with complex needs. There may also be a link between Caregivers of children with complex needs and coping strategy uses with Cognitive Fusion, Emotion Regulation and Adult Attachments as predictors within the model, creating a direct effect. The focus of this research is the Indirect Effect which is when Cognitive Fusion, Emotion Regulation or Adult Attachment is proposed as a mediator of the relationship between Caregivers of children with complex needs and coping strategy usage. The mediators are seen as linked with coping strategy choice, with the ultimate potential to influence coping strategy usage.

FIGURE 5 Proposed model of mediators of coping in caregivers in children with complex needs



3.1 Aims of this research

Caregivers of children with complex needs are under-investigated. As highlighted in the introduction and the systematic review, there is a lack of identification and understanding of these caregivers. The stress of the multiple demands of having a child with additional needs and caregivers coping is widely accepted. Despite this knowledge, little research is conducted on complex needs and how coping may differ for caregivers of children with complex needs. How caregivers cope with complex needs is important as the coping resources called upon may be different. Consideration of physical and non-physical caring requirements as well as severity of condition and the pile up demands of additional children who may have additional care requirements could be of vital importance when caregivers are trying to manage stress through coping strategy usage.

This research aimed to identify the coping strategies used and more importantly, establish other variables which could influence the strategy choice of caregivers of children with complex needs. The more knowledge that is gained, the more help could be provided to a unique population who may require a more robust coping strategy than caregivers who are typically identified and investigated.

The aim of this research was to test the above model in caregivers of children with complex needs compared to caregivers of children in a non-complex group.

The purpose of the present study was to:

- Investigate the common Coping strategies used by caregivers of children with complex needs
- Explore the mediating role of Adult Attachment, Emotion Regulation and Cognitive Fusion in the relationship between Complexity and Coping in caregivers of children in complex need

The next section describes the study design and measures utilised. Details of each of the coping and potential mediator measurement utilised and incorporated into the online questionnaire will be described. Other tools

designed to gather caregiver data on the severity, type and complexity of their child or children's conditions are also presented. After the mechanism and processes of the questionnaire have been described, results are displayed and then discussed in the subsequent chapter.

4. Methods

This chapter provides details of the processes and measures used to gather data to test the research questions through use of an online questionnaire. Broad descriptions of the categories are described, followed by a more detailed description of the source and design of the categories.

4.1 Research Design

This research used complexity as a predictor variable which was derived from four classifications in relation to the health of children of the Caregiver participants: Healthy Control group, Physical, Non-Physical or Complex conditions. Further classifications based on Severity and Complexity were also utilised. For Severity, participants were in one of three categories: No Difficulty, Mild/Moderate and Severe/Profound. Complexity in participants was categorised as Low, Medium or High. For the analysis, a complexity score was devised based on elements including Type and Severity of condition as covariables.

4.1.1 Categorical Variables:

The caregiver participants were categorised by three main factors of the child's condition: Type of need, Severity and Complexity of condition:

Type of Need categorised the children's condition into one of four groups: Healthy Control group, Physical, Non-Physical or Complex. The Complex category comprised of participants caring for children with both physical and non-physical conditions. Type of need covered all conditions the child may be experiencing.

A comprehensive description of potential illnesses and conditions or disorders caregivers' children were experiencing was required. These categories were sourced from research by Bath University for The Disability Data Collection for

Children's Services for the Department for Children, Schools and Families. (Porter *et al.*, 2008). The condition types were created to cover the full range of both physical and psychological additional needs. The broad categories included a descriptor to enhance understanding.

The classifications used for the Physical categories within the study were:

- *Health or medical needs* (e.g. allergies, asthma, blood pressure, cancer, circulation, diabetes, epilepsy, HIV, ME, MS, cerebral palsy) and
- *Sensory impairment* (e.g. blind or multisensory impairment, deaf, hearing impairment, visual impairment).

The classifications used for the Non-Physical categories within the study were:

- *Cognitive or learning needs* (e.g. dyslexia, moderate learning difficulty, profound and multiple learning difficulties, severe learning difficulty, specific learning difficulty),
- *Mental health difficulties* (e.g. anxiety, depression, eating disorder, phobias),
- *Autism or Autistic spectrum disorder*, (e.g. Asperger's syndrome, Pervasive Development Disorder-not otherwise specified (PDD-nos.))
- *Behaviour, emotion and social development needs* (e.g. attention deficit (hyperactivity) disorder, conduct disorder, emotional and behavioural difficulties).
- *Speech language, communication or interaction needs and difficulties*; speech and language difficulties
- *Other additional need* (a comment box was provided for this choice).

Severity of Need Originally comprised of five categories: No Difficulty, Mild, Moderate, Severe and Profound. This meant for the analysis that between Severity, Complexity and type of condition, there were twelve categorical tiers of data. The Severity of Need categories were collapsed into three levels instead of five as the merging of the categories were still indicating the same range of results. This was done by recoding participant data into three categories (No Difficulty, Mild/Moderate and Severe/Profound). Participants of children with no severity difficulty were coded as category one (No Difficulty) Mild or moderate needs were coded as category two (Mild/Moderate) and severe or profound as category three.

The measure of severity of the child's condition was taken from Porter et al's. (2007) report. Severity of condition was measured on a six-point selection where participants were asked "If your child has an additional care requirement on an average day, how much does this impact on your life? Choices were:

- "No difficulty",
- "Mild – occasionally interferes with everyday activities and only in a minor way",
- "Moderate – intermittent but regular limitation of normal activities",
- "Severe – frequent and significant impact on daily activities",
- "Profound – unable to take part in a number of activities",
- "I don't want to answer this question"

There was also a comment box provided advising "This may be a difficult question as it can vary so much day by day, if it's hard to choose, you can pick "I don't want to answer this question" and leave a comment in the box."

Complexity of need Comprised of three levels of complexity: Low, Medium and High. The participants were also categorised into a Complexity or Non-Complexity group.

4.1.2 Creation of the Complexity Scale:

The complexity score was designed specifically for this research by allocating points which increased dependent on the number of children and presence of conditions the caregiver was experiencing through their child or children as indicated by the questionnaire. The score started at 1 for participants with one child with no additional need. This score increased in relation to compound demands. Each factor, such as the number of children the participant cared for, or the presence of each element of any physical or non-physical condition, increased the score by one point ranging from 1 to 27.

The highest score of 27 was for a participant who had five children with eleven individual physical and non-physical conditions reported. These conditions included learning difficulties, medical problems, autism, speech and language difficulties and sensory issues such as blindness or deafness. There were also high scores on the severity of the children's conditions (14 points in total). If caregivers had children with only physical or only non-physical conditions, one additional point was added, and 2 points were added if both physical and non-physical conditions were present. So, a combination of the elements of type, severity and number of children was indicated by this complexity score. The range of complexity from 1 to 27 had a mean of 6.9 and a median of 6. Therefore, any participant with a complexity score of 7 or above was categorised as complex (n=56), 46% of the participant sample. The data were categorised by converting the category into a dummy variable named Complexity. Those caregivers in the Complexity group were categorised as 1 (one) and those in the Non-Complexity group were categorised as 0 (zero).

4.2 Coping and the Proposed Mediators

The constructs investigated were Coping, Adult Attachment Emotion Regulation and Cognitive Fusion. These constructs were derived from four individual standardised questionnaires which were included in the survey: The R-COPE (Zuckerman & Gagne, 2003), Attachment Style Questionnaire, (ASQ; Feeney, Noller & Hanrahan, 1994), Emotion Regulation Questionnaire (Gross & John,

2003) and Cognitive Fusion Questionnaire (CFQ, Gillanders et al., 2010) The statements within these questionnaires were used to extrapolate 13 Dependent Variables:

R-COPE (five variables: Self-Help, Accommodation, Approach, Avoidance and Self-Punishment), this tool was used to measure coping strategy with 40 statements.

Emotion Regulation (two variables: Reappraisal and Suppression). This tool measured Emotion Regulation with 10 statements.

Attachment Style Questionnaire (five variables: Confidence, Discomfort with Closeness, Relationships as Secondary, Need for Approval, Preoccupation with Relationships), this tool was used to measure adult attachment styles with 40 statements. The tool also produced two additional sub-sets which were a combination of the statements which related to Attachment Anxiety and Attachment Avoidance.

Cognitive Fusion (one score variable ranging between fused/diffused). This tool measured Cognitive Fusion with 13 statements.

4.3 Participants

Recruitment of participants was conducted through Facebook and forum placement of online survey link. The survey was posted on the researcher's Facebook page and specialist condition specific Facebook groups. Friends and family also shared and promoted the link on their Facebook pages. Although the link was placed on numerous specialist condition specific forums, such as Adders (ADD/ADHD online group) and Epilepsy Scotland. Posting the link on Facebook resulted in the most successful uptake. This was gauged by real-time monitoring of uptake when links were posted on new sites or promoted on

Facebook. When the link was posted on the forums there was no uptake indicated on the Survey Monkey notifications software. The primary method of collection was snowball sampling and it was anonymous in regards participant location. It would appear real-time statistics and “end of survey comments” by participants would indicate Facebook as the predominant collection mechanism utilised by participants.

The inclusion criteria for this sample were caregivers of children under the age of 18 who lived in the UK or ROI. The total sample comprised of 121 adult participants (mean 39.12, SD 7.52). The majority were female (n= 101) and married (n=79) with one (n=46) or two (n=40) children as can be seen by table 7. The mean age of the 121 participants was 39.12 (SD 7.52)

TABLE 7 Summary of Participant Demographics

Relationship Status			Gender			Number of Children		
Cat.	No.	%	Cat.	No.	%	Cat.	No.	%
Single	19	16%	Fem.	101	83%	one	46	38%
Divorce	15	12%	Male	19	16%	two	40	33%
Married	87	72%	Decline	1	1%	three	26	22%
						four plus	9	7%

The categorisation of the participants by their child’s condition by type, severity and complexity is displayed in table 8.

TABLE 8 Summary of Participants by child's condition

Participants categorised by the child's condition								
Type			Severity			Complexity		
Category	No.	%	Category	No.	%	Category	No.	%
No Additional Need	41	34%	No severity	44	36.50%	Low	46	38%
Non-Physical Need	39	32%	Mild/Moderate	43	35.50%	Medium	49	40%
Physical Needs	12	10%	Severe/Profound	34	28%	High	26	22%
Complex Needs	29	24%						

Between the 121 participants, there were 250 children and of these children, 127 children had no additional care needs. The remaining 123 children had a vast range of specific conditions which fell into the questionnaire categories as indicated by table 9. The participant demographics indicated many caregivers' children were experiencing a combination of conditions. There were 89 participants with children experiencing a combination of conditions; only 41 participants had children with no additional needs. Many caregivers had children with multiple overlaps in all three categories of additional needs, physical and non-physical needs. Due to the overlap highlighted, it was not possible to compare methods of coping used by caregivers of children with specific conditions, such as autism or learning difficulties.

TABLE 9 Description from questionnaire for child's classification of condition from 250 children in the sample

Condition description:	Times reported
<i>No addition care requirements.</i>	127
<i>Health or medical needs</i>	52
<i>Sensory impairment</i>	14
<i>Cognitive or learning needs</i>	38
<i>Mental health difficulties</i>	21
<i>Autism or Autistic spectrum disorder</i>	50
<i>Behaviour, emotion and social development needs</i>	27
<i>Speech language.</i>	37
<i>Other additional need</i>	13

4.4 Materials

An average of 20 minutes was required to complete the online questionnaire. The core questionnaire comprised 116 questions in total with 6 demographic enquiries and 110 statements. The six questions covered Age and Gender of the participants and Age, Gender, Condition type and Severity of the child's condition. The 110 statements were from the measurement tools incorporated within the survey. There was a process flow which allowed additional child's details to be captured in turn, after which each participant was directed onto the next stage of the questionnaire to respond to the 110 statements. In addition to the 110 statements and six questions, there were five opportunities for additional comments. The next section described the key questionnaires utilised in the survey which cover coping and the potential mediators of coping: Adult Attachment, Emotion Regulation and Cognitive Fusion.

4.4.1 R-COPE questionnaire

Coping was assessed using the R-COPE (Zuckerman and Gagne, 2003), which is a 40-statement self-report questionnaire (see Appendix 8.2). The R-COPE is a revised version of the original COPE questionnaire, designed by Carver, Scheier and Weintraub (1989). The R-COPE was designed to measure coping employed in reaction to difficulties, examining behaviours and actions in reaction to challenging situations, tendencies and external coping style utilisation.

The R-COPE generated five subscales: Self Help, Approach, Accommodation, Avoidance and Self Punishment. Each of the sub-scales is composed of eight statements. The R-COPE used a 7-point Likert scale: "Never", "Almost Never", "Sometimes", "Neutral or decline to answer", "Often", "Nearly Always" and "Always".

Self Help is related to sustaining emotional wellbeing and how emotions are expressed, such as the likelihood of talking about feelings.

Self-Punishment investigates self-rumination and blame utilisation, measured by how often problems are brooded over and reports of being self-critical.

Accommodation addresses accepting and reframing negative outcomes.

Approach relates to problem solving strategies, when taking direct action and active steps towards dealing with problems is adopted.

Avoidance concerns denial and blaming others, investigating feelings of being unable to deal with situations considering the potential reaction of stopping trying to deal with the problem.

Participants were asked: “When I find myself in a challenging or difficult situation:” then the statements were presented. Table 10 indicates typical statements which indicates the type of actions associated with each coping strategy in the R-COPE:

TABLE 10 Typical statements by coping strategy for the R-COPE

Sub-scale	Typical statement
Self-Help	I allow myself to show how I feel about things
Accommodation	I work on staying positive even when things look bad
Approach	I make a plan of action
Avoidance	I try to forget the whole thing
Self-Punishment	I criticise or lecture myself

The R-COPE internal reliability is reported as high at between 0.87 and 0.92 by Zuckerman and Gagne (2003) study.

4.4.2 Attachment Style Questionnaire (ASQ)

The Attachment Style Questionnaire (Feeney, Noller and Hanrahan, 1994) is a 40 statement self-report questionnaire designed to measure adult attachment interactions. (see Appendix 8.5) The five sub-scales are Confidence (8 statements), Preoccupation with Relationships (8), Discomfort with Closeness (10), Need for Approval (7) and Relationships as Secondary (7). There are two additional sub-sets which combine statements from different statement to produce Avoidance (16) and Anxiety (13) categories. A 7-point Likert style was used: “Strongly Disagree”, “Disagree”, “Slightly Disagree”, “Neutral or decline to answer”, “Slightly Agree”, “Agree” and “Strongly Agree”.

Confidence describes how easy it is for the participant to get close to others and if they feel liked and well respected.

Pre-occupation with Relationships describes worry about relationships, considering reliance on others loving them and feelings of being left out or alone.

Need for Approval describes the participant reports importance of being liked and pleasing others rather than themselves as a priority and low self-esteem is indicated.

Discomfort with Closeness measures the level to which a person reports unwillingness to share, is self-dependent or indicates difficulty with reliance on others.

Relationships as Secondary describes situations where asking for help is deemed a failure and achievements are considered more important than relationships.

Participants were asked: “When you are experiencing a challenging, stressful or difficult day, how much do you agree or disagree with the following statements?” Table 11 demonstrates the emotional perspective associated with the Adult attachment sub-scales in the ASQ.

TABLE 11 Typical statements of sub-scales of the ASQ

Sub-scale	Typical statement
Confidence	I feel confident about relating to others
Pre-occupation with Relationships	I worry a lot about my relationships with others
Need for Approval	I wonder why people would want to get involved with me
Discomfort with Closeness	I find it hard to trust other people
Relationships as Secondary	To ask for help is to admit that you are a failure

The alpha coefficients range reported between 0.76 and 0.84 by Feeney, Noller and Hanrahan (1994). Two further sub-scales can also be calculated: Attachment Anxiety and Attachment Avoidance.

Attachment Anxiety is a combination of 13 items compiled from the Need for Approval, Preoccupation and Confidence factor statements. The statements focus on elements such as worry or fixation on relationships and difficulty relating to others. Worry about fitting in and measuring up to other people's expectations are typical characteristics of the statements combined for Attachment Anxiety.

Attachment Avoidance comprised of 16 items from Avoidance, Discomfort with Closeness, Relationships as Secondary and Confidence. These 16 items focus on difficulty with trust and reluctance to depend on others. Higher scores would also indicate a preference for being self-reliant and keeping others at an emotional distance. The two sub-scales were an average of the statement scores with higher scores reflecting greater attachment anxiety or avoidance. It was these two scales combining elements of all the main sub-factors of the ASQ which were used in the key analysis of the data.

4.4.3 Emotion Regulation Questionnaire

The Emotion Regulation Questionnaire (Gross and John, 2003) is a ten-statement tool designed to measure Emotion Regulation (Appendix 8.4). The two sub-scales are Reappraisal and Suppression. Participants respond using a 7-point Likert scale: “Strongly Disagree”, “Disagree”, “Slightly Disagree”, “Neutral or decline to answer”, “Slightly Agree”, “Agree” and “Strongly Agree”.

Reappraisal relates to controlling the personal meaning events have for the individual. Reappraisal is evident when negotiating stressful situations by taking an optimistic attitude, reinterpreting what they find stressful, and making active efforts to repair bad moods.

Suppression emphasises controlling one’s behavioural responses to events, masking inner feelings and clamping down on outward displays of emotion. Suppressors are less clear about what they are feeling, less successful at mood repair, and view their emotions in a less favourable or accepting light.

Participants were advised: “You are now going to be shown some statements about your emotional life, in particular, how you control (that is, regulate and manage) your emotions. The questions below involve two distinct aspects of your emotional life. One is your emotional experience, or what you feel like inside. The other is your emotional expression, or how you show your emotions in the way you talk, gesture, or behave. Although some of the following questions may seem similar to one another, they differ in important ways.” Table 12 displays typical statements in relation to differences between reappraisal and suppression. These two variables are extracted from the Emotion Regulation questionnaire.

TABLE 12 Typical statements of sub-scales of the ER questionnaire

Sub-scale	Typical statement
Reappraisal	I control my emotions by changing the way I think about the situation I'm in.
Suppression	When I am feeling negative emotions, I make sure not to express them.

Gross and John (2003) reported the alpha coefficients range between 0.68 to 0.75 for Suppression and between 0.75 and 0.82 for Reappraisal, demonstrating acceptable reliability.

4.4.4 Cognitive Fusion Questionnaire

The Cognitive Fusion Questionnaire (Gillanders et al. 2010) is a 13-statement inventory which measures psychological flexibility based on a continuum from fused to diffused. Distancing oneself from thoughts is known as “cognitive diffusion” and its counter process is “Cognitive Fusion”.

When *fused*, a person acts on thoughts as though they are literally true, cognitive events come to dominate behaviour and experience over other sources of behavioural regulation, and he or she becomes less sensitive to direct consequences. In counselling terms, diffusion interventions aim to “unhook” thoughts from actions and to create psychological distance between a person and their thoughts. Table 13 demonstrates the difference between fused and diffused thoughts in relation to the statements used in the CF sub-scales. (Appendix 7.3) Participants were advised to: “Please read the question below and rate it closest to how you feel with 1 being Never True and 6 being Always True”

TABLE 13 Typical statements of sub-scales within the CF questionnaire

Sub-scale	Typical statement
Fused	I over-analyse situations to the point where it's unhelpful to me
Diffused	I find it easy to view my thoughts from a different perspective

The score is a numeric scale of 1 being “Never” to 6 being “Always true” and 7 being “I decline to answer”. There were four statements which were diffused and nine which were fused. The four diffused statements were reversed which meant the more fused a person’s thought processes were, the higher the score

would be. Excluding a declined response, the score could range between 13 and 78. Gillanders et al. (2010) reported the Cronbach's alpha coefficient as 0.86, which indicates good reliability.

4.5 Ethics

The study was independently reviewed and approved by Edinburgh Napier University Ethical Review Committee. Participants had to electronically consent before access to the survey was granted. Right to withdraw was provided throughout the survey and the design assured confidentiality and anonymity. Details of helplines were provided in case people required additional support or information. Contact details of an independent contact not linked with the study were also provided.

4.6 Procedure

Participants were initially directed to the primary information page (appendix 8.6). Agreement to participate was gained by ticking a box to progress. Confirmation of being a caregiver of a child under the age of 18 and a resident of UK or ROI were then required to allow access to the survey. All measures were presented electronically via Survey Monkey.

After having read the information and given consent, participants were then presented with further information on the second page regarding ethical considerations (Appendix 8.7). The second page displayed right to withdraw, contact and verification details, confidentiality reassurance and anonymity confirmation. Participants were advised that at the end of the survey, they would be provided with the chance of providing a password or phrase. This word or phrase could be used until a specified date had passed, after which time their results would be incorporated in the survey and it would not be possible to withdraw them to protect anonymity. Participants were also advised that the "exit this survey" button was displayed at the top right of every page.

The survey requested information about demographics such as gender, age, number of children, and type of disability. Following this, the questionnaires were presented. The ASQ was first, then the questions on support were followed by the ER and CF questionnaires, with the R-COPE being the last questionnaire. Comment boxes were provided in strategic places to clarify or invite further remarks during completion of the scale.

At the end of the survey, telephone and website information for Samaritans and Parentline were provided, in case an unintentional emotional response was triggered by a question or statement. A debrief was provided as well as a comment box provided and contact details were given again. Participants were given the opportunity to request further information, summary of results or leave additional comments.

5. Results

5.1 Research Questions

The findings of the present study will now be described. As a reminder, the purpose of this study was to:

- Investigate the common Coping strategies used by caregivers of children with complex needs
- Explore mediation and the role of Adult Attachment, Emotion Regulation and Cognitive Fusion in the relationship between Complexity and Coping in caregivers of children in complex need.

5.2 Analysis of variance.

To explore the initial group differences between the Complexity and Non-Complexity groups of caregivers, Independent Sample T-test were run for each coping strategy, grouped by the complexity and non-complexity. The five Coping strategies (Self-Help, Accommodation, Approach, Avoidance and Self-Punishment) were explored for group differences. There were no mean group differences for caregivers coping strategy scores when the Complexity of condition group was compared to the Non-Complexity Group (Table 14.)

TABLE 14 Comparison between complexity groups for Coping strategies

Subscales	Group	Mean	Std. Dev.	F	t*	Sig
Self Help	Non-Complex	25.35	7.13	0.15	-.16	0.87
	Complex	25.55	7.11			
Accommodation	Non-Complex	30.09	5.70	0.54	-0.44	0.66
	Complex	30.56	6.15			
Approach	Non-Complex	29.36	6.49	0.67	-1.01	0.31
	Complex	30.51	5.85			
Avoidance	Non-Complex	19.37	4.22	0.28	0.77	0.44
	Complex	18.79	4.11			
Self-Punishment	Non-Complex	24.50	6.14	0.05	-.15	0.88
	Complex	24.67	6.26			

t* Degrees of freedom (119)

This research is about factors which may influence or mediate the caregiver's choice of coping strategy use. The factors investigated as proposed mediators of coping strategy use were Adult Attachment, Emotion Regulation and Cognitive Fusion. Before these factors were explored through mediation analysis, difference between groups was explored through the use of grouping by Complexity on Independent Sample T-test. As the adult attachment subscales of Attachment Anxiety and Attachment Avoidance are composite scores extrapolated from the overall ASQ statements utilised, the five attachment subscales they derived from were not included in the analysis to control for multi-collinearity.

The exploration of the data with T-tests indicated there were no differences between the Non-complexity and Complexity groups for coping strategy usage. Adult Attachment Avoidance and Cognitive Fusion usage was significantly higher for caregivers in the Complexity group compared to the Non-Complexity group (Table 15).

TABLE 15 Group Differences in Complexity for Coping Mediators

Mediators	Complexity	Mean	Std. Dev	F	t ^	Sig
Attachment Anxiety	Non-Complex	3.49	0.51	0.58	-0.63	0.53
	Complex	3.55	0.54			
Attachment Avoidance	Non-Complex	3.47	0.49	2.76	-2.74	0.01*
	Complex	3.69	0.38			
Reappraisal	Non-Complex	24.32	4.70	1.24	0.37	0.71
	Complex	23.96	5.68			
Suppression	Non-Complex	13.58	3.01	2.19	-0.87	0.39
	Complex	14.12	3.70			
Cognitive Fusion	Non-Complex	39.28	12.26	6.72	-2.25	0.03*
	Complex	43.95	10.52			

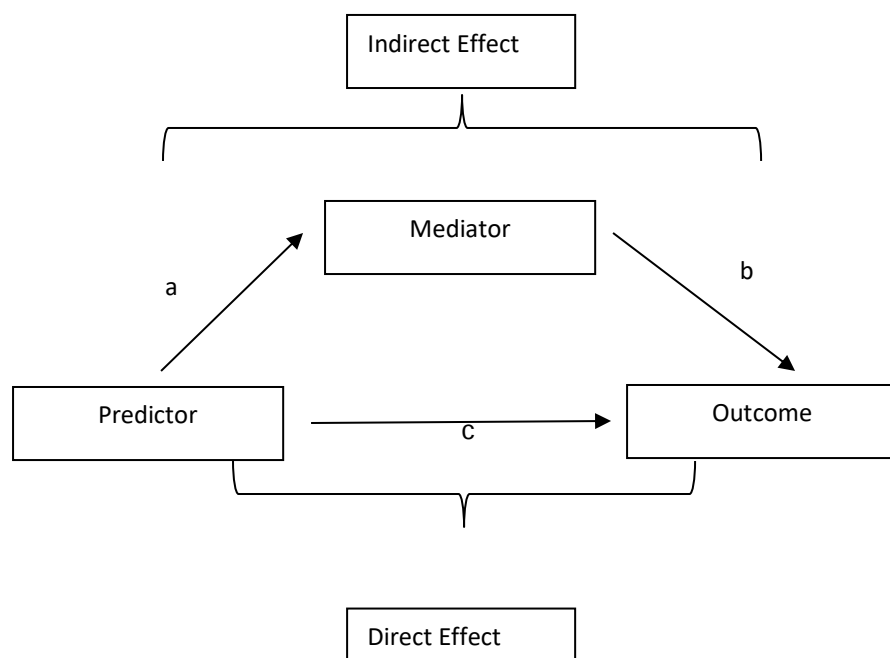
***Significant, ^ DF=119**

The T-tests indicated the groups differed on some of the proposed mediators; Attachment Avoidance and Cognitive Fusions differed between the Complexity and Non-Complexity groups of caregivers. These interactions occurring between complexity and the mediators suggested further investigation was justified.

5.3 Mediation

To determine the nature of the relationship other elements may have on influencing an outcome, which in this case was coping strategy usage, Mediation was chosen as the main analysis method for this research. Mediation refers to the relationship between a predictor variable and an outcome variable being explained by a third variable (the mediator) (figure 6). Mediation occurs if the strength of the relationship between the predictor and the outcome is significantly influenced when the mediator is included (Fields, 2014).

FIGURE 6 Basic mediation model



$a \times b$ = indirect effect, c = direct effect of the predictor on the outcome.

Mediation considers the Direct, Indirect and Total Effect of these interactions. The **Total Effect** measures the effect of the predictor on the outcome without

the inclusion of the mediators. **Direct Effect** is the effect of the predictor on the outcome when the predictors are included in the model. **Indirect Effect** is the effect of the predictor on the outcome through the use of the mediators. The Indirect effect of the mediators on the outcome is the key focus of this research.

To carry out the mediation, the PROCESS analysis tool developed by Andrew Hayes (2012) was installed onto IBM SPSS 22. The Hayes PROCESS tool is designed to measure direct and indirect relationships by running as an additional programme within the SPSS regression analysis calculator, creating additional options and relevant outputs. Hayes software is also designed to conduct bootstrap analyses on potential mediators. Bootstrap analysis allows the data to be treated as a population from which repeated smaller samples can be taken and replaced each time before each new calculation is ran. The results produce data which can extract confidence levels and indicate the significance of indirect effects on the main factors being investigated.

Mediation has traditionally though to have required a total effect of there being a relationship between the predictor and the outcome before the analysis could be conducted with Baron & Kenny (1986) being held as the gold standard. This traditional approach is now being reconsidered by more current thinking which suggests that the rejection of further analysis is premature (Rucker, Preacher, Tormala & Petty, 2011; Zhao, Lynch & Chen 2010). When re-examining Baron & Kenny's (1986) recommendations, Zhao et al. (2010) presented a decision tree (p201) which provided a framework to mediation theory and principles which provide guidelines on how to approach data when there is no significant effect on the direct "c" path. The suggestion was that an unexplained direct path could indicate omitted mediators, therefore exploration is valid. Zhao et al. (2010) also suggested the only requirement for mediation is that the indirect effect $a \times b$ be significant. This research is taking the more current perspective within the investigation.

The PROCESS analysis software was carried out to measure the significance of Coping Strategies in caregivers of children with complex needs. It was then

used to establish if Emotion Regulation, Cognitive Fusion and Adult Attachment were significant mediators of the relationship between Caregivers of children with complex needs and coping strategies utilised.

Each of the five coping strategy subsets (Self-Help, Accommodation, Approach, Avoidance and Self-Punishment) were used in turn for the mediation analyses as outcome variables. The direct relationships between Complexity and the coping strategies were measured as well as the significance of each potential mediator of coping. This produced five models (figures six to ten), with total, direct and indirect relationships calculated for each of the coping strategies being investigated.

The next section will look at each of the five Coping strategies individually as each strategy has unique characteristics which may be influenced differently by the mediators.

5.3.1 Self-Help

There was no significant total effect between Complexity and coping Self-Help strategies without the inclusion of Cognitive Fusion, Emotion Regulation or Adult Attachment. There was also no significant direct effect between Complexity and Self-Help usage when the potential mediators were included in the model as predictors (figure 7). Self-Help did not have a significant total effect or direct effect indicated. Although there was an indication of a significant indirect effect of Self-Help on Complexity through Attachment Avoidance usage (Table 16) the lack of direct effect significance means this is not valid.

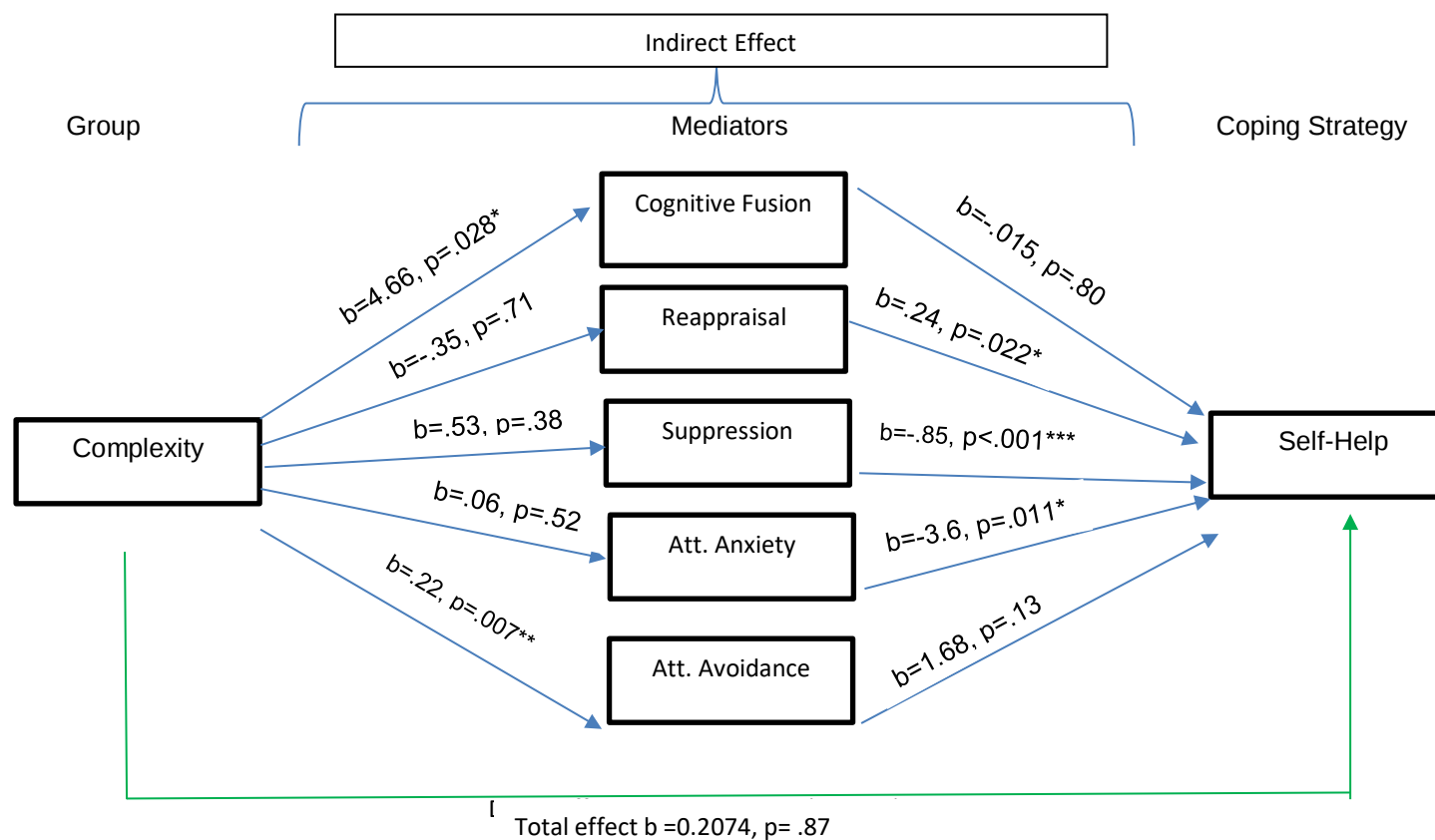
TABLE 16 Indirect effects of mediators of Self-Help in Complexity group

Self-Help			
Mediator	Effect	Lower Level Confidence Interval	Upper Level Confidence Interval
Cognitive Fusion	-0.07	-0.77	0.45
Reappraisal	-0.09	-0.83	0.28
Suppression	-0.45	-1.62	0.54
Attachment Anxiety	-0.08	-0.90	0.13
Attachment Avoidance	-0.08	-1.86	-0.19*

*Where a Confidence Interval contains a .0 value, the mediator has a non-significant effect. If the Lower Confidence Interval is a negative value and the Upper Confidence Interval is positive, it straddles the zero value, and it is therefore not significant. Indirect effect is the effect of complexity on self-help through the use of the mediators.

Overall results indicate Self-Help usage is not significant in caregivers of children with complex needs and no mediators had a direct effect on this relationship.

FIGURE 7 Mediators of Self-Help Coping strategies in caregivers experiencing Complexity with their child's condition



Total effect measures usage of self-help in complexity, without mediators, Direct effect is when the mediators are controlled for.

Significant at level $<.05=^*$, $<.01 = ^{**}$, $<.001 = ^{***}$

5.3.2 Accommodation

The model produced for the Accommodation coping strategy usage (figure 7) indicated that although there was not an overall direct link between Complexity and Accommodation coping strategy usage, there was a significant direct effect when the mediators were controlled for. This indicated that, when mediators were included within the model, Accommodation coping strategy usage was significant for caregivers in the Complexity group when Cognitive Fusion was included. When the direct relationships between Complexity and Accommodation were examined including mediators, Cognitive Fusion was found to have a negative relationship with Accommodation. When Cognitive Fusion had lower scores, use of Accommodation coping strategies was higher.

Cognitive Fusion was also indicated as an indirect mediator of Accommodation. The indirect effect mirrored that of the direct effect, in that it mediated use of Accommodation as a coping strategy. Lower scores in Cognitive Fusion for caregivers of children in the complexity group indicated higher use of Accommodation coping strategies (Table 17).

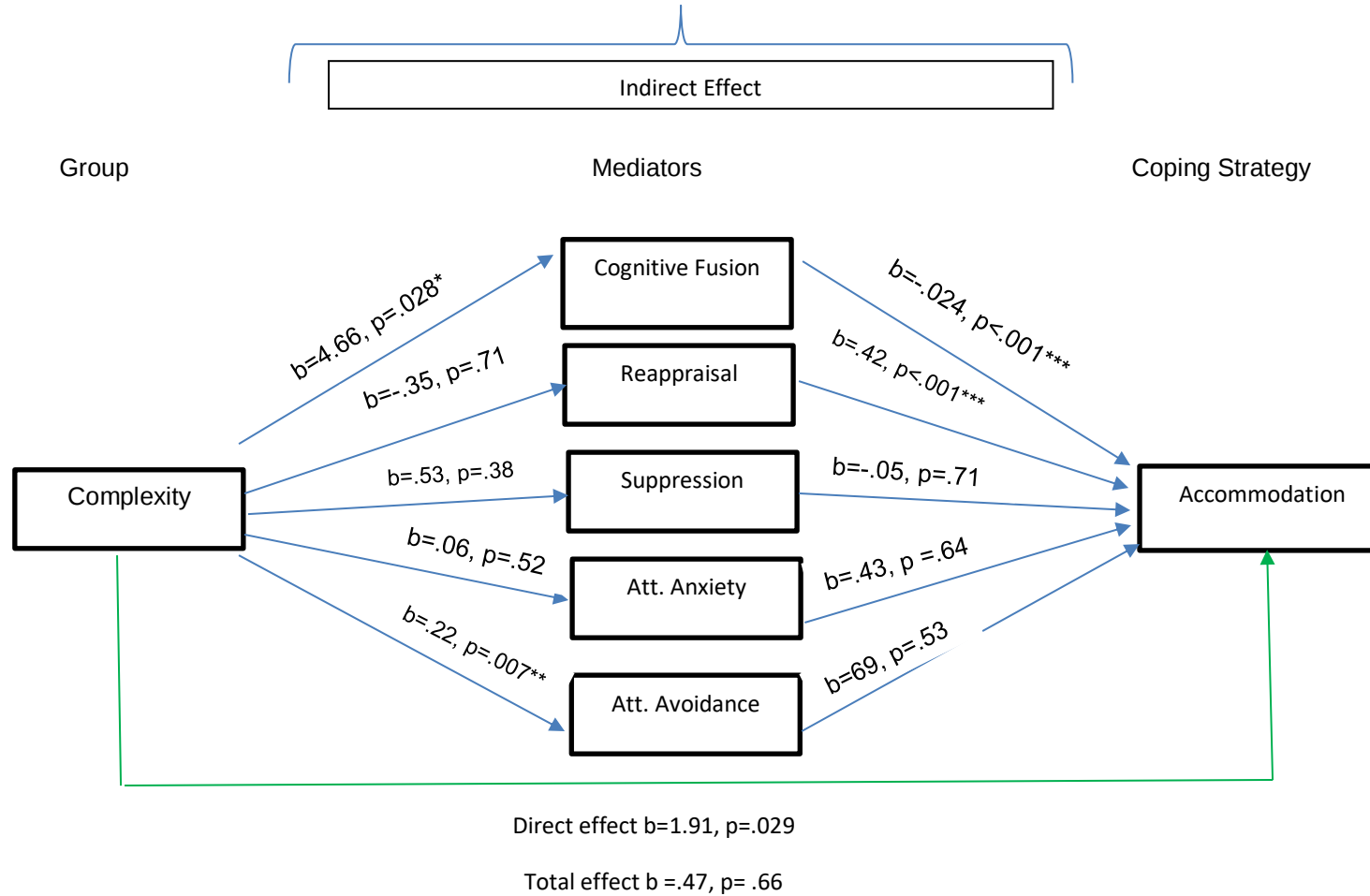
TABLE 17 Indirect effects of mediators of Accommodation in Complexity Group

Accommodation			
Mediator	Effect	Lower Level Confidence Interval	Upper Level Confidence Interval
Cognitive Fusion	-1.44*	-2.64*	-0.13*
Reappraisal	-1.14	-1.10	0.52
Suppression	-0.15	-0.40	0.09
Attachment Anxiety	-0.26	-0.12	0.54
Attachment Avoidance	-0.15	-0.89	0.25

*Significant as the intervals have not crossed over the zero threshold.

Overall results indicate that when Cognitive Fusion scores were decreased, Accommodation coping strategy usage increased for caregivers of children with complex needs. This interaction occurred when Cognitive Fusion scores were considered as both a direct predictor and a mediator within the model.

FIGURE 8 Mediators of Accommodation coping strategies in caregivers experiencing Complexity with their child's condition



Total effect measures usage of accommodation in complexity, without mediators, Direct effect is when the mediators are controlled for.

Significant at level $<.05=^*$, $<.01=^{**}$, $<.001=^{***}$

5.3.3 Approach

As can be seen in figure 8, there was no total effect between Complexity and Approach. There was a significant direct effect of the mediators when they were controlled for within the model. Cognitive Fusion had a direct relationship with both Complexity and Approach. Use of Approach coping strategies significantly increased when caregivers had lower Cognitive Fusion scores.

Cognitive Fusion was indicated as having a significant indirect effect on use of Approach strategies when Complexity was present (Table 18). Increased usage of Approach strategies was linked with a decrease in Cognitive Fusion behaviours for caregivers of children with complex needs.

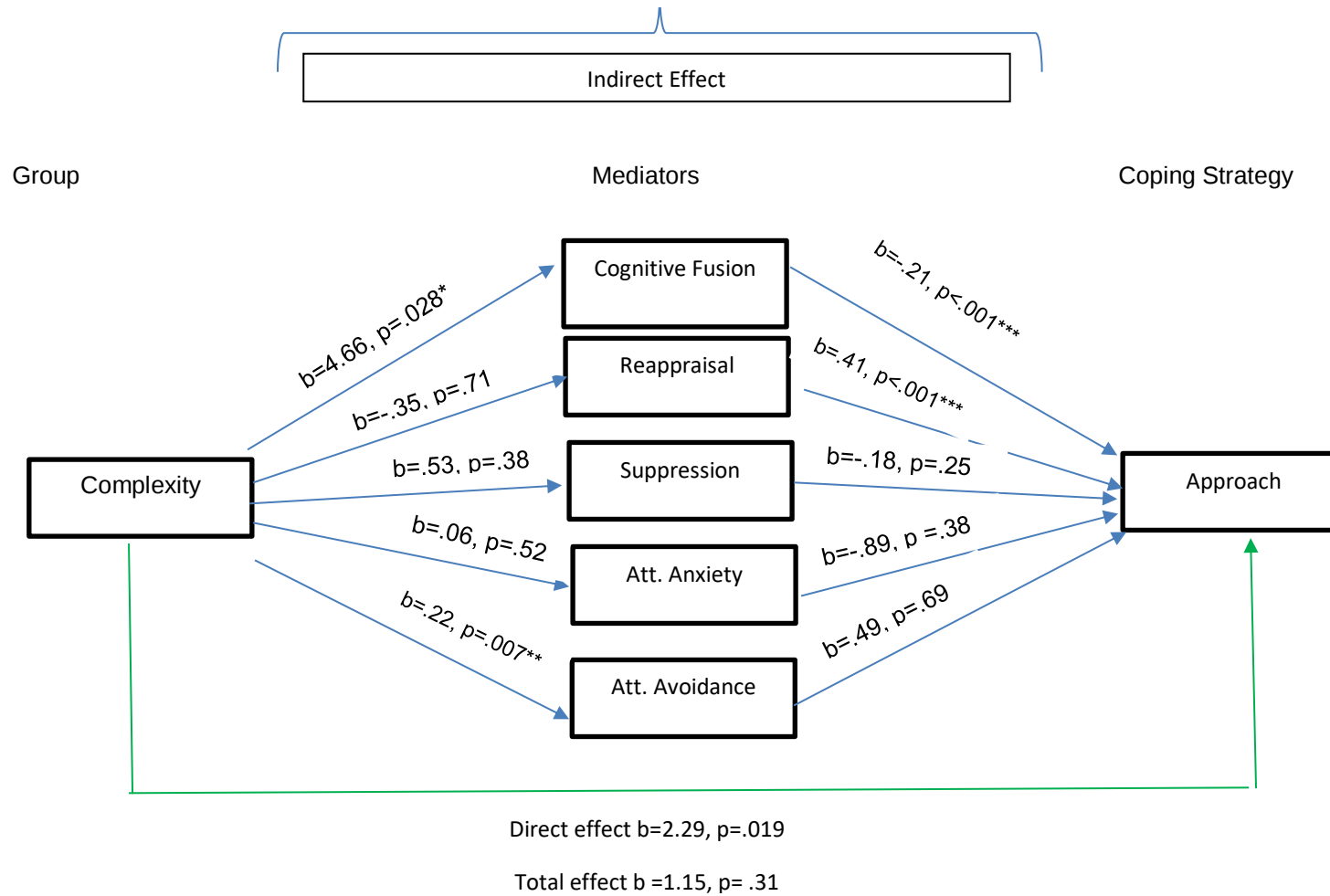
TABLE 18 Indirect effect of mediators of Approach in the Complexity group

Approach			
Mediator	Effect	Lower Level Confidence Interval	Upper Level Confidence Interval
Cognitive Fusion	-0.95	-2.42*	-0.09*
Reappraisal	-0.15	-1.05	0.51
Suppression	-0.10	-0.71	0.09
Attachment Anxiety	-0.05	-0.81	0.09
Attachment Avoidance	0.11	-0.35	0.80

*Significant as the intervals have not crossed over the zero threshold.

Overall results indicated that Cognitive Fusion was a mediator for Approach coping strategy usage. Cognitive Fusion had a direct effect on Approach coping strategies as well as an indirect effect through its use for caregivers in the Complexity group.

FIGURE 9 Mediators of Approach coping strategies in caregivers experiencing Complexity with their child's condition.



Total effect measures usage of Approach in Complexity, without mediators, Direct effect is when the mediators are controlled for.

Significant at level $<.05=*$, $<.01=**$, $<.001=***$

5.3.4 Avoidance

Where the previous three coping subsets of Self-Help, Accommodation and Approach, are adaptive strategies, Avoidance and Self-Punishment are more maladaptive actions. This is mirrored in the analysis as Cognitive Fusion changed from having a negative relationship interaction into a positive one in the Avoidance and Self-Punishment models. The Total Effect of Coping Avoidance usage in caregivers in the Complexity group was not significant without the inclusion of the mediators. There was a direct effect interaction for Cognitive Fusion and Coping Avoidance. When Cognitive Fusion scores were high, Coping Avoidance strategy usage also increased (Figure 9).

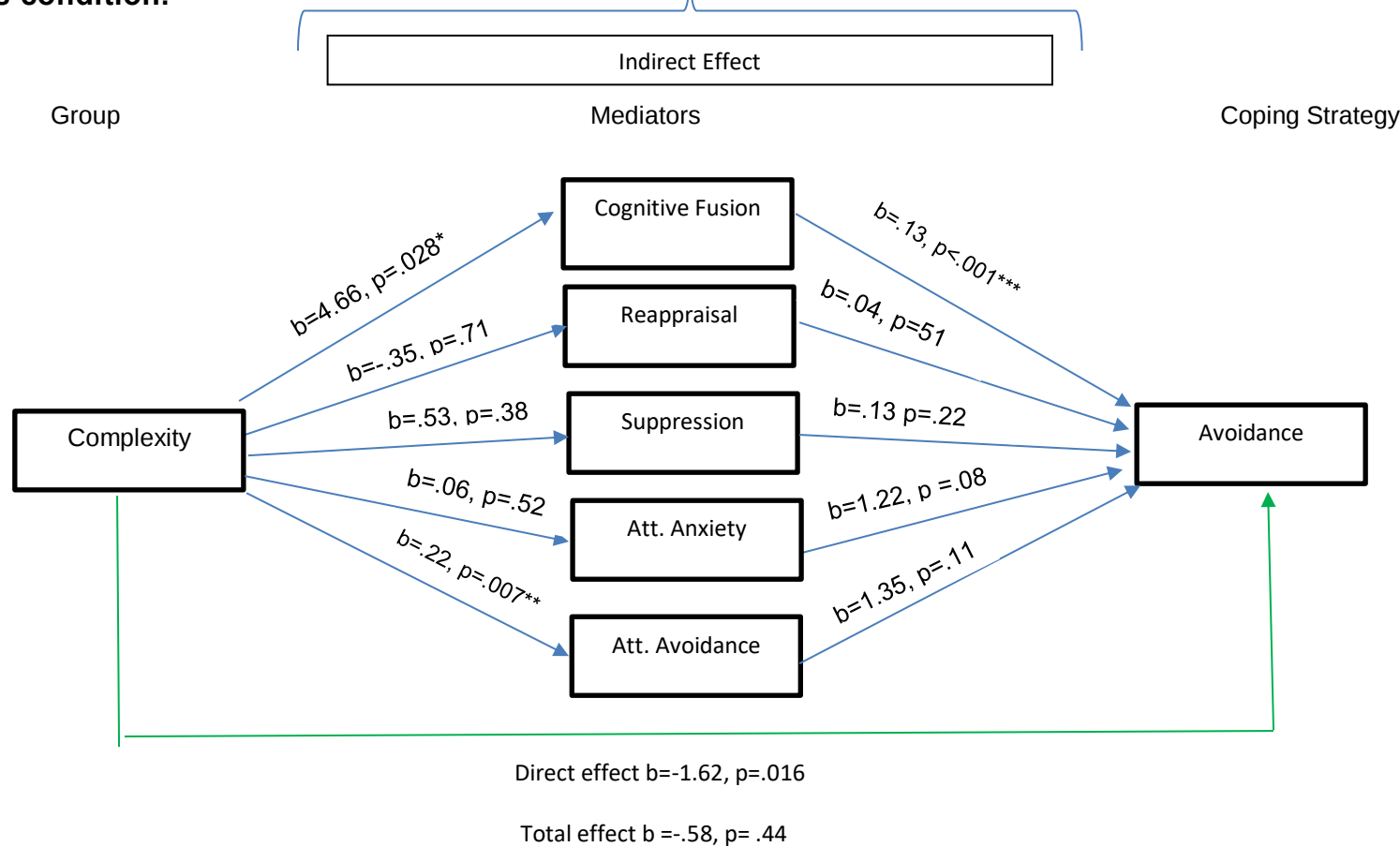
Overall results indicted when the indirect influences of the mediators were examined, both Cognitive Fusion and Attachment Avoidance were indicated as being significant positive mediators. Higher scores in Cognitive Fusion and Attachment Avoidance mediated to increase Coping Avoidance strategy use in caregivers of children in the complexity group (Table 19).

TABLE 19 Indirect effect of mediators of Coping Avoidance in the Complexity group

Coping Avoidance			
Mediator	Effect	Lower Level Confidence Interval	Upper Level Confidence Interval
Cognitive Fusion	0.62*	0.11*	1.40*
Reappraisal	-0.01	-0.31	0.09
Suppression	0.07	-0.08	0.50
Attachment Anxiety	0.07	-0.10	0.59
Attachment Avoidance	0.30*	0.04*	0.83*

*Significant as the intervals have not crossed over the zero threshold.

FIGURE 10 Mediators of Avoidance coping strategies in caregivers experiencing Complexity with their child's condition.



Total effect measures usage of Avoidance in Complexity, without mediators, Direct effect is when the mediators are controlled for.

Significant at level $<.05=*$, $<.01=**$, $<.001=***$

5.3.5 Self-Punishment

As with the other coping strategies there was no total effect interaction between Complexity and Self-Punishment (figure 10). Use of Self-Punishment in caregivers in the complexity group was not significant without the inclusion of Cognitive Fusion or Attachment Avoidance as mediators in caregivers of children with complex needs.

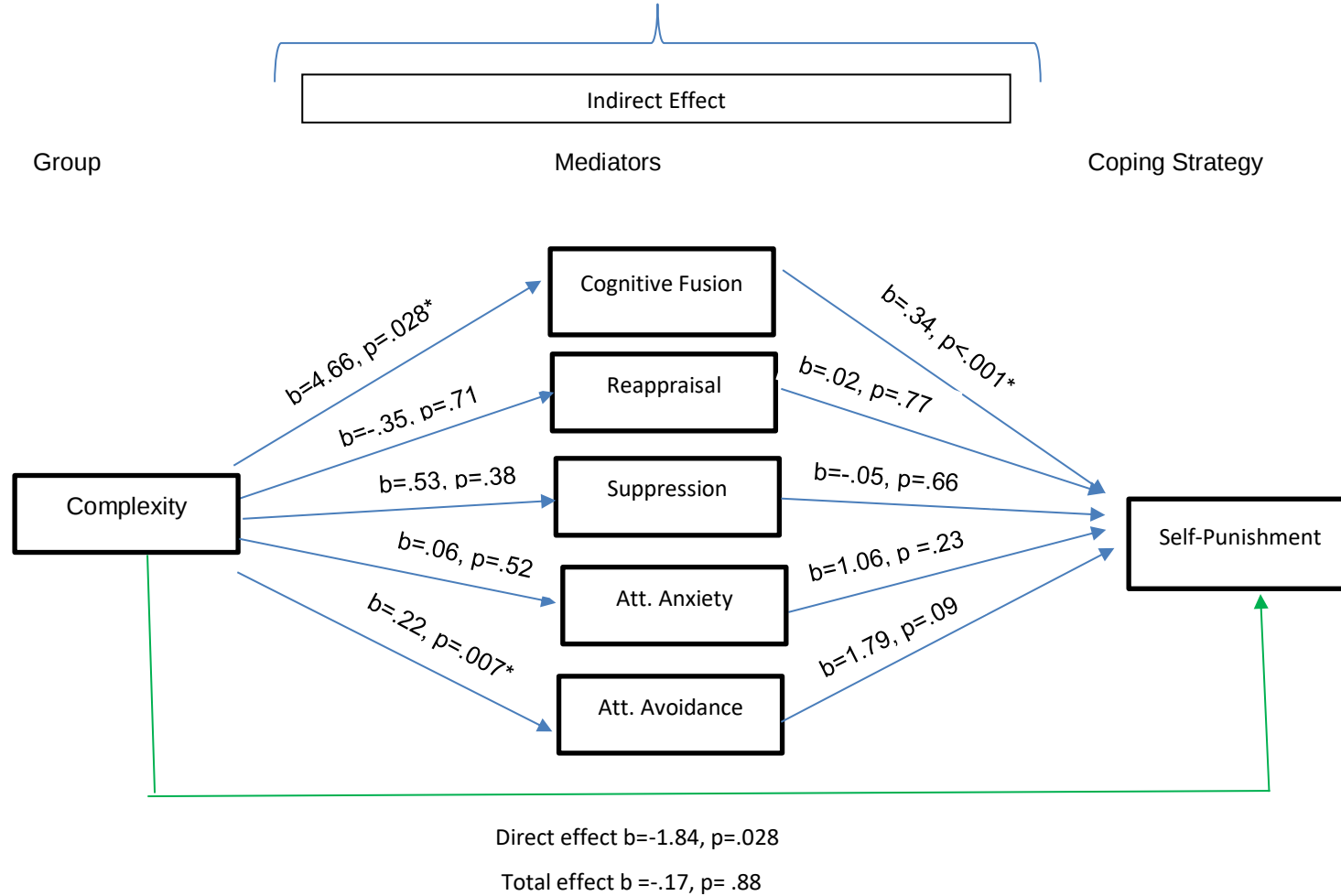
Cognitive Fusion had a direct effect interaction with Self-Punishment in the Complexity Group. High scores in Cognitive Fusion was linked with an increase in Self-Punishment strategies. The indirect effect indicated that higher scores in Cognitive Fusion and Attachment Avoidance led to higher usage of Self-Punishment coping strategies in caregivers of children with complex needs (Table 20).

TABLE 20 Indirect effect of mediators of Self-Punishment in the Complexity group

Self-Punishment			
Mediator	Effect	Lower Level Confidence Interval	Upper Level Confidence Interval
Cognitive Fusion	1.59*	0.19*	3.13*
Reappraisal	-0.01	-0.35	0.09
Suppression	-0.03	-0.48	0.13
Attachment Anxiety	0.06	-0.11	0.66
Attachment Avoidance	0.39*	0.02*	1.16*

*indicates significant effect

FIGURE 11 Mediators of Self-Punishment coping strategies in caregivers experiencing Complexity with their child's condition



Total effect measures usage of Self-Punishment in Complexity, without mediators, Direct effect is when the mediators are controlled for.

Significant at level $<.05=^*$, $<.01=^{**}$, $<.001=^{***}$

5.4 Summary of Results

The mediation analysis did not find any significant association between complexity and any of the coping strategies. When Adult Attachment, Emotion Regulation and Cognitive Fusion were excluded from the model, caregivers of children in the Complexity group showed no difference in coping strategy usage compared to caregivers in the Non-Complexity group.

When Cognitive Fusion, and Attachment Avoidance were included in the model, as indirect effect mediators, Caregivers in the Complexity group used significantly different coping strategies compared to the Non-Complexity group.

As can be seen by table 21, it was only the Self-Help coping strategy were non-significant for usage in caregivers of children in the complexity group.

TABLE 21 Direct effect of Complexity on each Coping Sub-scale

Coping Sub-sets	Effect	SE	t	p
Self-Help	2.00	1.14	1.75	0.083
Accommodation	2.24	0.89	2.51	0.013*
Approach	2.61	1.00	2.62	0.010*
Avoidance	-1.71	0.69	-2.49	0.014*
Self-Punishment	-1.84	0.83	-2.22	0.028*

*Indicates significance

Cognitive Fusion and Attachment Avoidance were the two variables which mediated the relationship between caregivers in the complexity group and coping strategy usage. As table 22 demonstrates, lower Cognitive Fusion scores led to higher use of Accommodation and Approach. Higher Cognitive Fusion scores led to higher Self-Punishment and Avoidance usage.

TABLE 22 Direction of the impact of the mediator on coping strategy usage in the complexity group.

Increased use of the mediator:	Results in a:	In the usage of the coping strategy below (when complexity is present):
Cognitive Fusion	decrease	Accommodation
	decrease	Approach
	increase	Avoidance
	increase	Self-Punishment
Attachment Avoidance	increase	Avoidance
	increase	Self-Punishment

Attachment Avoidance and Cognitive Fusion were mediators in the relationship between complexity and coping for caregivers of children in the complexity group. When Cognitive Fusion scores were decreased, the adaptive coping strategies Accommodation and Approach usage increased and vice versa for the Complexity group. When Cognitive Fusion scores increased, the maladaptive coping strategies of Avoidance and Self-Punishment usage increased. Coping Avoidance and Self-Punishment strategy usage in the Complexity group also increased as Attachment Avoidance scores increased. Emotion Regulation and Attachment Anxiety did not mediate between complexity and coping strategy usage in caregivers of children with complex needs.

6. Discussion

The aims of this study were to investigate the common Coping strategies used by caregivers of children with complex needs. Mediation and the role of Adult Attachment, Emotion Regulation and Cognitive Fusion in the relationship between Complexity and Coping in caregivers of children in complex need were also explored. This chapter will discuss the findings based on what is known about coping strategies in caregivers of children with complex needs, how the aims fit in with the literature. Implications for coping theory and practice are discussed as well as strengths and limitations of the study. This is followed by suggestions for further research and conclusions based on this study's findings.

6.1 What is known about coping strategies in caregivers of children with complex needs?

There were no studies identified in the systematic review conducted for this study which investigated coping in caregivers of children with complex needs. The systematic review found that coping in caregivers of children with any type of additional care requirement were typically investigated in isolation or with limited comparison (see appendix 8.1 for breakdown by study). There was sometimes a cursory check of any co-morbidities indicated in the systematic review, but this was often used as a screening mechanism for exclusion rather than being incorporated in the analyses (Dabrowska & Pisula, 2010; Pisula & Kossakowska, 2010). Even without specifically recruiting for caregivers of children with complex needs and the criteria being any caregiver of children under the age of 18, over two thirds of the participants reported multiple care demands. This indicates there may be far more caregivers of children with complex needs than the literature suggests and very little is known about their coping strategy usage.

The systematic review highlighted that coping in caregivers of children with additional needs was typically investigated as a basic construct (see appendix 8.1). The underlying characteristics of the categories and strategies produced

by the measures being used to ascertain coping were not typically a factor of the investigation. Inconsistencies of approach were demonstrated by the vast range of coping measures utilised and the selective use of elements within the studies. The individual and selective approach utilised meant difficulty of comparison even with the same condition or measure were used in different studies. Coping strategy usage was not always found to be significant in caregivers of children with additional needs in many of the studies reviewed (McConkey et al. 2008; Mirsaleh et al., 2011; Murphy et al., 2008; Rodrigue et al., 1990; Solem et al., 2011; van den Borne et al., 1999). Some coping strategies were found to be more commonly reported with Avoidant Coping the most frequently reported coping strategy for caregivers of children with additional needs (Al-Yagon, 2011; Margalit et al., 1992). Additional constructs were often investigated, as such as SOC (Al-Yagon, 2011; Margalit et al., 1992; Pisula & Kossakowska, 2010; Solem et al. 2011) and depression, (Barrera et al., 2004; Madu & Roos, 2006; van den Borne et al., 1999) however they were alternative factors and relationships between these constructs and coping were not typically considered. Very little is known about coping in caregivers of children with complex needs.

6.2 Key findings based on the study's aims

The first aim of the study was to investigate the common coping strategies used by caregivers of children with complex needs. Basic analysis indicated Coping strategy usage was found to be no different to that of the Non-Complexity group when compared with the Complexity group. If the traditional approach was followed where potential mediators of coping were not considered, this study would have added to the many studies which indicate coping is not significantly used by caregivers of children with additional needs.

The second aim of the study was to explore mediation and the role of Adult Attachment, Emotion Regulation and Cognitive Fusion in the relationship between complexity and coping in caregivers of children in complex needs. The

inclusion of these three mediators highlighted a previously unidentified relationship between the three mediators of Adult Attachment, Emotion Regulation and Cognitive Fusion with coping strategy usage in caregivers of children with complex needs.

The results of this study have indicated that the mediation by Cognitive Fusion and Attachment Avoidance have an indirect effect on coping strategy usage in caregivers of children with complex needs. Complexity had a direct effect on coping strategy usage when the mediators were incorporated in the model.

The key findings were that Cognitive Fusion and Attachment Avoidance were mediators of coping in caregivers of children with complex needs. Self-Help was the only coping strategy which was found to be non-significant for usage when used directly as a predictor of coping of caregivers in the complexity group.

For this study, an increased score in Cognitive Fusion indicated increased fused thought processes where behaviour is characterised as overly influenced by cognition (CFQ, Gillanders et al., 2010). Increased scores in Cognitive Fusion for caregivers of children with complex needs were associated with a decrease in use of the adaptive coping strategies of Accommodation and Approach. An increase in Cognitive Fusion scores for the complex needs group was also associated with increased usage of the maladaptive strategies of coping Avoidance and Self-Punishment. For caregivers of children in the complexity group, as Attachment Avoidance usage increased, Coping Avoidance and Self-Punishment strategy usage also increased.

Cognitive Fusion statements used in the measurement chosen for this study (CFQ, Gillanders et al., 2010) were based on how much participants felt they struggled with their thoughts, over-analysed situations and becoming entangled in certain thoughts. When Cognitive Fusion is at its most maladaptive, thoughts can cause distress, emotional pain and cause those who experience high Cognitive Fusion to have difficulty doing the things they most want to do. In this

study findings indicated that as Cognitive Fusion scores increased, Coping Avoidance and Self-Punishment strategy usage also increased in caregivers of children with complex needs.

Coping Avoidance is indicated when participants report denial or reapportioning blame to others, giving up attempts to go for goals and withdrawal from situations R-COPE (Zuckerman & Gagne, 2003). Self-Punishment is about self-blame, dwelling on problems, self-criticism and ruminating on problems. There are commonalities between these three constructs, Cognitive Fusion is focused on internal emotions, focused on how much psychological flexibility a participant experiences as they cope with their internal thought processes (Gillanders et al., 2010). Coping Avoidance and Self-Punishment statements are based on reactions to the maladaptive thoughts. Avoidance has statements like “I try to forget the whole thing”, “I pretend that it isn’t really happening”. Self-Punishment has statements including “I realise I brought the problem on myself”, “I blame myself” (Zuckerman & Gagne, 2003). These coping statements are more about reactions towards thoughts which are also common themes within the Cognitive Fusion statements. The drives and internal motivations these three constructs are based on may be from different measurement tools but the commonalities and theoretical themes are evident.

The opposite directional relationship was discovered with Cognitive Fusion and coping Accommodation and Approach compared to coping Avoidance and Self-Help. Decreased Cognitive Fusion scores mediated and increased Accommodation and Approach coping usage. Accommodation and Approach coping strategies are adaptive and positive reactions to situations. Accommodation usage is indicated when participants accept difficulties and react accordingly: “I look for something good in what is happening”, “I work on staying positive even when things look bad”. Approach is more direct, with statements relate to making action plans, moving towards the difficulty and working out tangible strategies to cope with situations (Zuckerman & Gagne, 2003). Lower Cognitive Fusion scores were associated with increased adaptive coping strategies in caregivers of children with complex needs.

The results indicate that for caregivers of children with complex needs, reducing Cognitive Fusion scores would lead to decreased Coping Avoidance and Self-Punishment strategy usage and increased Accommodation and Approach coping usage. Reducing Attachment Avoidance scores would also appear to be key to reducing Coping Avoidance and Self-Punishment usage and increases in Self-Help usage. Reduction of maladaptive mediators is indicated as increasing adaptive coping strategy usage in caregivers of children with complex needs.

Total effect was not found to be significant in the model, which meant that Coping strategy usage was not significantly different between the complexity and the non-complexity group without the incorporation of mediators. The presence of Complexity was associated with having a direct effect on coping strategy choice in Accommodation, Approach, Avoidance and Self-Punishment, but not Self-Help. The direct effect includes the mediators however only Attachment Avoidance and Cognitive Fusion were indicated as having an indirect mediating effect on the relationship between Complexity and Coping strategy use. Emotion Regulation and Attachment Anxiety do not have a mediating role for caregivers of children with complex needs for coping strategy usage.

6.3 Findings in relation to previous literature and aims of this study.

An examination of previous literature indicated that coping in caregivers of children with complex needs was not investigated. Coping was rarely the main focus of investigations in caregivers of children with any additional need. Appendix 8.1 lists the vast array of other measurements often included in the studies. Although coping was included with many other constructs, mediation of these constructs as an influencer of coping strategy was not considered within the literature. The aims of this study were to investigate common coping strategies and the potential role of mediators in caregivers of children with complex needs.

Coping has been investigated in relation to caregivers of children with additional needs, however no studies were identified which considered mediators of coping. Coping has been investigated as a mediator of other constructs such as between attachment style and marital satisfaction (Lussier, Sabourin & Turgeon, 1997). Lussier et al. (1997) found that Avoidant Attachment was related to Avoidance coping strategies. Coping Avoidance strategies acted as a mediator between anxious/ambivalent attachment style and marital adjustment. In a study on 515 undergraduate students by Wei, Heppner and Mallinckrodt (2003), perceived coping was investigated as a mediator between adult attachment avoidance and psychological distress (identified by depression, hopelessness, anxiety, anger, and interpersonal problems). Perceived coping was found to mediate the relationship between attachment anxiety and psychological distress. There was also a study of 372 graduate students by Wei, Heppner, Russell and Young (2003) which found that ineffective coping mediated the relation between maladaptive perfectionism and depression. Although some studies have been conducted which considered coping as a mediator, no study was identified which considered there may be mediators which influenced coping strategy usage.

Dardas & Ahmad, (2013) considered coping strategies as a mediator between stress and quality of life (QoL) in a study of 184 parents of children with autistic disorder. The coping strategy of “accepting responsibility” was a mediator of stress and QoL for the parents in the study. Seeking social support’ and ‘escape avoidance’ were moderator strategies in the relationship between stress and QoL. The “accepting responsibility” strategy was not interpreted as parent’s feelings of responsibility for the actual condition. The strategy was interpreted more as accepting responsibility for what needs to be done to manage the child’s condition. Taking responsibility was interpreted as adaptive by enhancing feelings of being in greater control. So, although mediators of coping have been rare and none were found with the parameters of the systematic review for this study, coping as a mediator of other constructs has been investigated within caregivers of children with additional needs.

The interpretation of the “accepting responsibility” coping strategy as moving towards the problem and working out how to accommodate the child’s condition within the parents’ environment appeared to be akin to the Accommodation and Approach coping strategies utilised in this current study. A closer look at the four statements utilised to ascertain parents’ use of Accepting Responsibility did not confirm this apparent similarity in strategies. The four-statements related to “accepting responsibility” in the study by Dardas and Ahmad (2013) were: “I criticized or lectured myself”, “I realized I brought the problem on myself”, “I made a promise to myself that things would be different next time” and “I apologized or did something to make up”. If these four statements were being compared to this study’s statements in the R-COPE (appendix 8.2), they would appear to identify more comfortably with coping Avoidance and Self-Punishment rather than Accommodation or Approach. The four statements of “accepting responsibility” do not appear to be adaptive strategies, although it had merit in considering this coping strategy as a mediator of QoL. The focus on the individual statements highlights the differences in the underlying constructs of the measurements used in coping studies and demonstrates that as well as larger theoretical problems, there are also basic methodological problems, which add to the inconsistencies and overall challenges inherent when investigation caregivers of children with additional needs.

Few studies have considered mediators when investigating caregivers of children with additional needs. As the systematic review highlighted, no studies were identified which considered any mediators of coping. A review of the literature highlighted that coping is traditionally viewed as a finite end result, rather than something which can be influenced by other factors. There are many factors that influence coping and this study highlighted type and severity of need, number of children, complexity and other factors such as Adult Attachment, Emotion Regulation and Cognitive Fusion. Other studies have highlighted different elements such as Dardas and Ahmed (2003) identifying coping as a mediator of QoL. The studies in the systematic review also considered many other concepts including SOC (Pisula & Kossakowska, 2010; Solem et al., 2011; Al-Yagon, 2011) and Depression (Madu & Roos, 2006; Barrera et al. 2004; van den Bourne et al., 1999). Although there were a vast

range of measures and constructs considered in the studies identified by the systematic review, none considered coping as being mediated by other measures or constructs.

The systematic review also highlighted a lack of investigation into caregivers of children with complex needs. No studies were identified in the systematic review which specifically investigated caregiver who were caring for a child or children with multiple care demands. The term “complex” was used in this study as a description where the caregiver’s child or children were experiencing physical and psychological difficulties. The systematic review highlighted that previous studies on caregivers coping were typically condition specific such as cancer (Barrera et al., 2004; Murphy et al., 2008) or Intellectual or learning difficulties (Al-Yagon, 2011; McConkey et al., 2008; Mirsaleh et al., 2011; Wang et al., 2011) and if co-morbidities were present, caregivers were typically excluded. Alternatively, one or two conditions were compared (Dabrowska & Pisula, 2010; Rodrigue et al., 1990; van den Bourne et al., 1999) but overlap of condition was not considered. The approach taken in the investigation for this study has indicated that these factors should be integral to any study on additional needs.

For the investigative element of this study, participants could respond if they had any children under the age of 18. All the caregiver’s children were enquired upon, quantifying the presence of any additional need and if an additional need was present, type and severity information was gathered. The data from this approach indicated that, when participants were specifically asked about all their children, multiple overlaps and co-morbidities in the children’s conditions were reported. This departure from the traditional approach of specific or limited comparison on one child was fruitful.

Results indicated out of the 121 participants in this study, 82 (68%) had at least one child with a condition. Between the 123 children identified as having any type of condition, out of the 250 children in the study, there were 252 instances

of a condition being reported. This data suggested that the focus on coping within the context of an individual condition, with little or no accounting for environment or other mediating factors, would appear to be flawed. Even without specifically recruiting for caregivers of children with complex needs and the criteria being any caregiver of children under the age of 18, over two thirds of the participants reported multiple care demands in their children.

As the quantitative element of this study have highlighted, there are fewer caregivers who are caring for one child with one condition than the systematic review would suggest. Little consideration has been given to the fact that caregivers will have other source of potential stress or responsibilities to manage. There are many influences and relationships between multiple factors which influence caregivers when they are within their family environment. The aims of this study to establish the coping strategies utilised by caregivers of children of complex needs and investigate the role of Adult Attachment, Emotion Regulation and Cognitive Fusion as mediators has been a worthwhile line of enquiry.

6.4 Strengths and limitations

6.4.1 Strengths

6.4.1.1 Theory

This study was the first to apply a specific complexity score for caregivers of children with additional needs. It was also the first study to propose a model which incorporated Adult Attachment, Emotion Regulation and Cognitive Fusion as mediators of coping strategy usage. The creation of the model of coping explored in this study has introduced a different theoretical approach to coping which has revealed new relationships not previously considered.

The review highlighted that traditional coping measures and the existing body of literature on caregivers of children with additional needs did not tell us enough about how coping works. Typically a coping measure such as the WOC is employed (Barrera et al., 2004; Hussain & Juyal, 2007; Madu & Roos, 2006;

Mirsaleh et al., 2011; Murphy et al., 2008; Paster et al., 2009; Pisula & Kossakowska, 2010; Rodrigue et al., 2009) and despite there being studies pointing to methodological weaknesses such as poor psychometric properties, unstable factor analysis and lack of cross-validation (De Ridder, 1997; Endler & Parker, 1990), it is often utilised in studies in caregivers of children with additional needs. The predominant theory applied to coping strategy usage is one of habitually dichotomous emotion/problem focused categorisation where “emotion focused” is viewed as maladaptive and “problem focused” is preferred (Mirsaleh et al. 2011; McConkey et al. 2008). The approach to coping measures was inconsistent making comparison highly problematic and this study highlighted the depth of the variation within the body of literature. There are very few systematic reviews of this scale and breadth and undertaking the review has highlighted the lack of coherent approach to coping in caregivers of children with additional needs as well as lack of investigation into complex needs.

The focus on potential mediators of coping for this study has given insights towards establishing how coping may work. The new approach towards coping has highlighted unexplored relationships with other key concepts which impact directly and indirectly on coping. This research has established there are mediators of the relationship between coping and caregivers of children with complex needs. This study highlighted a gap in the literature regarding the under-investigation of caregivers of children with complex needs and proposing a model of coping which has real life practical applications by establishing links with mediators which have therapy and intervention as an integral part of their design.

6.4.1.2 Methodology

The questionnaire was electronic, using social media as its distribution method, allowing contact with many participants who may not usually get polled. There were many caregivers who took part who did have children with complex needs,

so the research polled a “hard to reach” participants not typically investigated. When participants were being asked to take part in the survey, Facebook comment feedback was given by caregivers which indicated they felt it was refreshing to be asked about themselves and how they were coping, as most support is focused on the child and their wellbeing.

The survey was the first to combine the four questionnaires utilised and this new approach identified relationships between the constructs: Coping, Emotion Regulation, Cognitive Fusion and Adult Attachment, which previous literature had not investigated. Using mediation as the analysis method in this study was atypical and identified previously undiscovered relationships and a potential new different theoretical and methodological approach.

The study highlighted the complexity caregivers experience by including consideration of the impact of larger families, condition severity and co-morbidities many caregivers are coping with in their children. Instead of taking the traditional approach of focusing on a caregiver as if they live in a vacuum with only one child with one condition to care for, this study was inclusive, considering all the children’s mental and physical conditions accounting for the impact of severity. Complexity was indicated as being a significant factor in determining coping strategy choice with strong relationships being identified when Cognitive Fusion, Adult Attachment and Emotion Regulation were included in the model. Mediation and bootstrapping is a fresher approach than traditional methods of analysis and highlight again that a new way of looking at participants, measurements and type of analysis is needed to understand coping, the role of mediators, caregivers of children with additional needs and the impact of complexity of children’s conditions on caregivers.

6.4.2 Limitations

6.4.2.1 Theory

The focus on more overall combination of complexity of condition and environment made it impossible to be more specific about a child’s individual condition. The advantage of focusing on one specific condition is that it could highlight condition based successful strategy use for caregivers in isolation:

however, this study has highlighted the benefit of inclusion of consideration of accumulation of demands on caregiver resources despite the lack of ability to ascertain impact of one specific condition.

This research indicated that mediators are key to the significance of coping use in caregivers of children with complex needs. Coping may be a by-product with other factors such as Cognitive Fusion, Emotion Regulation and Adult Attachment playing a bigger role when internal resources are required to deal with a stressful environment or situation. This study has drawn attention to the concept that the underlying theoretical perspective taken when investigating coping is flawed. The dichotomous values typically referred to with studies are often basic, with coping often found to be insignificant as an influencer. Subscales are often specifically factored to suit individual investigations; resulting in inconsistency and difficulty in comparisons of coping between studies. Perhaps utilising coping as the key measure is a weaker theoretical approach and could be interpreted as a limitation of this study. Coping itself may be an outdated measure or construct, which may be useful as a factor in conjunction with other influential constructs but is not enough on its own. At the very least, more care and consideration should be used when coping is being applied to studies. Other constructs have better adaptability and potential for incorporation into therapies and interventions in a way coping does not readily lend itself to in isolation.

6.4.2.2 Methodology

As with most quantitative investigations, this study is a snapshot of a specific moment and results could vary depending on personal stress levels at the time. The survey was online and accessed by caregivers with a certain level of media familiarity, if participants are more likely to use social media, there is a possibility they do not fully represent the caregiver population.

Risk of bias with a one-person systematic review should be acknowledged particularly with the high volume of studies to filter and review. Attempts were made to mitigate this by duplicating electronic database filter searches and

comparing resulting number of papers identified, to ensure selection filters were sufficient. Exclusion of studies was based strictly on specific exclusion criteria. Key specific areas were consulted and reported in each paper, to avoid ambiguity of inclusion. There is a risk of bias in the specific coping measures which were included or excluded based on what constitutes a coping measure. The view of coping being an action based external construct may have excluded studies which interpret coping from a different perspective. This thesis highlights the difficulties when measuring coping as the lack of one definition is part of the problem.

The lack of specific stress measure could be considered a weakness when studying in relation to coping. A measure could have been included which enquired about how much stress participants felt under or how much they felt in control of their thoughts and emotions. This could have been utilised as a measure of the effectiveness of the coping strategy choice. The systematic review highlighted studies which included stress factors such as depression (Madu & Roos, 2006, Barra et al. 2004, van den Bourne et al., 1999) and this often impacted on outcomes. A score indicating levels of depression may have shed light on other influential stress factors or mediators and the caregiver's ability to cope. A specific measure of how much participants felt they were coping would have been beneficial. The omission of this, even if it was one or two statements such as "how stressed do you feel" or "how depressed do you feel" on a likert type scale may have had impact on the model. Although this omission may be interpreted as a weakness, the establishment of how the chosen mediators have impacted is perhaps the first step which is expanding the possibilities for future research.

The complexity scale was created for this research as there was no scale identified which considered number of children and multiple conditions. The categorisation of complex needs was assigned to caregivers with a complexity score above the mean and median of the sample. This could be seen as an arbitrary method of categorisation as results may be sample specific. This would require re-testing to establish if it could be valid for use in other

investigations The design was a straight additional score, tallying individual points but it makes the assumption that a child with two conditions would be scored the same as two children with a condition each. Although complexity was considered and tallied in, there may be a greater difficulty having the demands of different needs being divided between two children with individual requirements. The complexity score has been shown to be a successful indicator of group differences, even with a basic “counting up” of needs and demands, but there is room for refinement and development. There are many factors which could contribute towards complexity and how it impacts on a caregiver. Condition type, severity, overlap of conditions and multiple care needs including potential needs from other children in the family were key factors of the complexity score but other factors may be as important. Levels of support available, how the caregiver perceives they are coping, resources available including ease of access to medical or psychological assistance and socio-economic status could all be key factors which potentially feed into how complexity impacts on the caregiver. These factors were not included in this research and more in-depth consultation with caregivers of children with multiple needs could build a more comprehensive profile of potential factors in complexity of need.

The sample size and diversity of the participants in relation to their children’s multiple needs was highlighted by the high number of categories in the questionnaire design, however they were ultimately not used as using the individual categories made the diversity of the sample size unreliable for robust analysis. The collapsed categories and creation of the dichotomous complexity score was reliable and valid for the analysis however, categorisation on the original 12 sub-categories used for type, severity and complexity was required to establish the complexity classification developed. This design element of the questionnaire meant there were a lot of classifications used which could possibly be replaced by one overall complexity marker. In short, there may be a more efficient way of establishing complexity.

The final analysis categories for exploring the key mediators utilised amalgamated Attachment Avoidance and Anxiety scales, which meant that ultimately the participants were asked to respond to some statements which were not included in the analyses. A more efficient questionnaire with fewer statements may have resulted in a higher participation completion rate. The anonymity of the survey being online made withdrawal easy but if the questionnaire was quicker to complete with repetitive or unnecessary statements kept to a minimum, it might have generated a better response.

6.5 Implications for coping theory

The approach taken in regards to coping for this study highlighted that coping in caregivers of children with additional needs is typically investigated in a narrow capacity (Paster et al., 2009; Hussain & Juyal, 2007; Madu & Roos, 2006). The constructs are usually broken down to binary categories such as emotion focused or problem solving (Al-Yagon, 2011; Barrera et al., 2004; Margalit et al., 1992; McConkey et al., 2008; Mirsaleh et al., 2011; Murphy et al., 2008). The alternative is when the coping measures generate so many interactions, it is difficult to extrapolate the germane findings (Wang et al., 2011). If coping strategy usage is found to be significant as a factor in an investigation, analysis is often limited and the allocation of category is typically the conclusion (see appendix 8.1 for summary of results). The new approach taken in this study which included mediators within the proposed model was very successful. The model suggested mediators influenced the relationship between caregivers of children with complex needs and the coping strategies caregivers called upon. The inclusion of Adult Attachment, Emotion Regulation and Cognitive Fusion has highlighted how they act as influencers effecting coping strategy usage.

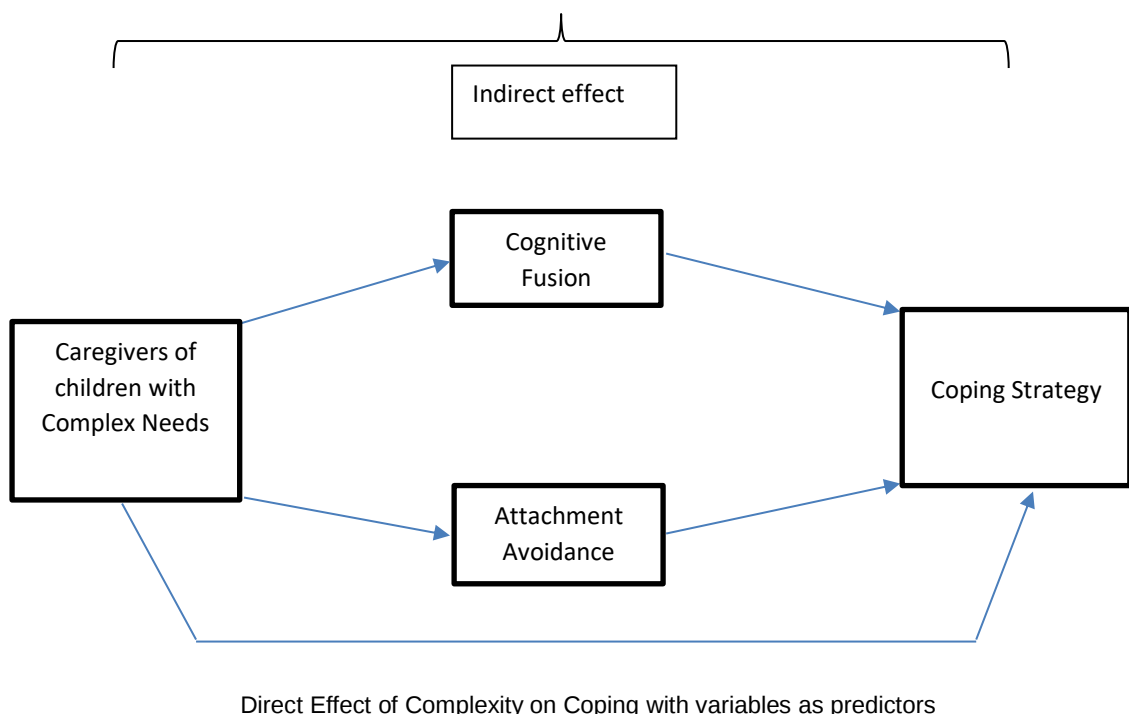
To this researcher's knowledge, the relationship between Adult Attachment, Emotion Regulation and Cognitive Fusion and Coping strategy usage has not been previously investigated. Key to this interaction between the mediators and coping was the direction of the effect. Decreased Cognitive Fusion scores were associated with increased usage of the adaptive coping strategies of Accommodation and Approach. Increased Cognitive Fusion scores were associated with increased maladaptive coping strategies of Avoidance and Self-

Punishment. The relationships identified by testing the model indicate the potential of enhancing adaptive coping strategies and minimising maladaptive coping strategy impact by focusing on the mediator of the coping strategies.

The identification of the significance of mediators within the model has highlighted the potential to influence coping strategy usage. Inclusion of mediators has shown that coping strategy usage is not as fixed and finite as the body of literature in coping in caregivers of additional needs appears to suggest.

The results have indicated that Emotion Regulation usage was not significant in the model and that Cognitive Fusion and Attachment Avoidance are the key mediators which predict the use of coping strategy in caregivers of children with complex needs. This means the model proposed at the beginning of this research is revised to the one depicted in figure 12.

FIGURE 12 Revised model of mediators of coping in caregivers of children with complex needs



6.6 Implications for practice

Cognitive Fusion and Attachment Avoidance were the mediators which influenced the coping strategy usage in caregivers of children with complex needs. Caregivers of a child with additional needs have been identified as experiencing more stress than other caregivers of children with no additional needs (Cousino & Hazan, 2013; Grootenhuis & Last, 1997; Rodenburg & Dekovic, 2007; Stuart & McGrew, 2009; van der Veek, 2009). It seems logical to suggest the additional burden of additional children, more severe conditions and a combination of physical and non-physical conditions and behaviours adds additional stress onto caregivers. As highlighted, complex needs is barely defined, investigated or considered in the literature on caregivers of children with additional needs. Caregivers of children with complex needs may be the most vulnerable and in need of extra support, but they are the least investigated within the literature.

This study has identified that Cognitive Fusion and Attachment Avoidance were key to influencing coping strategy use for caregivers in the complexity group. Providing counselling and therapy based on minimising the maladaptive elements of Cognitive Fusion and Attachment Avoidance should enhance adaptive coping strategies of Self-Help, Accommodation and Approach. The same focus on reducing Cognitive Fusion and Attachment Avoidance through therapy should also reduce preference for maladaptive coping strategies of Self-Punishment and Coping Avoidance.

In an online article, Wei (2008) stated attachment theory could be applied to understand how coping patterns developed and could help modify ineffective coping strategies. Wei (2008) suggested that clinicians should be aware that people with insecure attachment patterns such as attachment avoidance may use different coping strategies to cope with difficulties in their environment. The

recommendation was to attempt to break these patterns to enhance adaptive coping strategies by providing intervention.

In a study by Wei, Shaffer, Young, and Zakalik (2005), the findings were that by meeting a person's basic psychological needs for connection, competency and autonomy, those with attachment avoidance and anxiety could decrease feelings of shame, depression and loneliness. Connection, competency and autonomy are akin to some of the key aspects of Self-Help, Accommodation and Approach of seeking support, making plans and moving towards the situation rather than the withdrawal and self-blame associated with Coping Avoidance and Self-Punishment.

Cognitive Fusion has, to this researcher's knowledge, never been utilised as a mediator of coping strategy use in any study and no studies were identified which investigated caregivers of complex needs. This study identified increases in Cognitively Fused behaviours with increases in Coping Avoidance and Self-Punishment strategy usage. Fusion is measured on a continuum of how a person's cognitive events are internally evaluated and interpreted. Defused behaviour allows a person to be able to experience mental events which may not require to be acted upon. At the other end of the continuum, Fused behaviour can cause the person to be dominated and entangled by mental events (Gillanders et al., 2010). In Acceptance Commitment Therapy (ACT), Cognitive Fusion is one of the six factors utilised in this therapy. The general clinical goals of ACT are to "undermine the grip of the literal verbal content of cognition that occasions avoidance behavior and to construct an alternative context where behavior in alignment with one's value is more likely to occur" (Hayes, 2004, p651) In other words fused behaviour, when events are taken literally, is at its most harmful and alternative cognitions can be encouraged to replace them by focusing on adaptive context, helping the person towards seeing events as opportunities for growth rather than barriers, within their own value system.

ACT and particularly Cognitive Fusion are both associated with the traditional behavioural therapy of CBT. Although it may be suggested there are parallels with Attachment Anxiety and Avoidance maladaptive behaviours, such as the fixation of thoughts and ideas, it has never been associated as a mechanism which could potentially alter coping strategy usage. The relationships identified with this study had indicated both Cognitive Fusion and Attachment Avoidance have the capacity to enhance adaptive coping strategy usage. It would seem prudent to combine Cognitive Fusion therapy with Adult Attachment therapies to help individuals gain higher levels of perceived coping effectiveness.

6.7 Suggestions for further research

Many areas discussed in the study require further exploration. The model suggested for this study has proved meaningful; however, this is just the first stage of understanding caregivers of children with complex needs. As stated, the addition of a measure of stress or of how successful the adaptive coping strategies are in helping caregivers could be beneficial.

The complexity scale could benefit from further development. The method of accumulated score was quite basic, although it worked, there may be a more efficient approach which could be developed which may make it more easily transferrable to different populations. The level of complexity caregivers experience has been established as impacting on coping strategy usage and there is the potential for this research to be adapted to apply to anyone experiencing multiple care demands. Caregivers of adult child may experience similar calls on their resources but have additional considerations such as helping their child with autonomy, financial burdens, being elderly and having the worry of continuing care responsibilities. The lifespan of how the model may change for the caregiver as the child gets older would be a new area of investigation as complexity of condition could play a large part in how a caregiver's resources may be called upon as the child turns into an adult.

The type of relationship the caregiver has with the child, particularly when Adult Attachment has been indicated as a mediator, should perhaps also be explored

in the more traditional sense of parent/child attachment theory application. The number of children was factored in to the complexity score but not the temperament or personality of the child and how that may impact on the caregiver's use of inner resources. The child's attachment style as a factor of the child's personality could influence the mediators which in turn influence caregiver's coping strategy choice. This caregiver/child relationship could also potentially feed into the complexity score. Exploring the parent/child dyadic attachment style relationship could develop the model used in this study as it has the potential to be a mediator. The development of these aspects of lifespan, caregiver/child attachment style and further development of the complexity score could allow a more tailored specific approach which could inform the best method for provision of therapy or intervention by providing a more holistic approach.

6.8 Conclusion

This research identified a previously undiscovered relationship where internal thoughts and feelings mediated coping strategies in caregivers of children with complex needs. The systematic review was ambitious in its scope and confirmed that coping in caregivers of children with complex needs are not investigated within the literature. The Complexity score developed for this study had its weaknesses, but it could be viewed as a building block towards identification and analysis when investigating this specific population. Mediators of coping were a key element of this research which was also discovered to be an under-investigated subject area. In particular, Emotion Regulation, Adult Attachment and Cognitive Fusion have not been incorporated together in a study previously and this combination has proven to be fruitful. This research established mediators significantly influenced coping strategy utilisation for caregivers of children with complex needs. Investigating coping, mediators and complex needs across the existing literature has highlighted that further investigation is essential. More understanding on how coping works and the role mediation takes may not only help caregivers of children with complex needs, but could also tell us more about coping and why particular strategies are chosen by an individual.

The research suggests that reduced Attachment Avoidance and Cognitive Fusion scores for caregivers is linked with increased adaptive coping strategies. The adaptive behaviours of Self-Help, Accommodation and Approach focus on seeking support, active positive actions and acceptance of the situation with a positive perspective. These adaptive strategies contrast with Attachment Avoidance and Cognitive Fusion which are characterised by preference for superficial relationships, isolation, distancing from people, lack of trust, over-analysing, fixated thought patterns and problems letting go of upsetting thoughts. Working with caregivers of children with complex could confirm use of the maladaptive Attachment Avoidance and Cognitive Fusion behaviours. The use of adaptive Self-Help, Accommodation and Approach strategies and the potential to reduce use of Attachment Avoidance and Cognitive Fusion as coping strategies also requires further exploration.

Suggestions have been made as to what constitutes complex needs and elements which may mediate coping strategy use, however a qualitative element would be beneficial to build on this knowledge. A qualitative study could explore if caregivers of children with complex needs feel they are coping, if they believe they are using attachment avoidance and cognitive fusion and if the coping strategies they use are effective. This data could be used to refine the complexity score and increase our knowledge on mediators of coping and their influence, particularly in caregivers of children with complex needs but also in other groups of people experiencing multiple demands on their individual resources. Cognitive fusion and attachment avoidance have been indicated as mediating coping strategies in caregivers of children with complex needs, so the next stage would be to investigate why this is the case.

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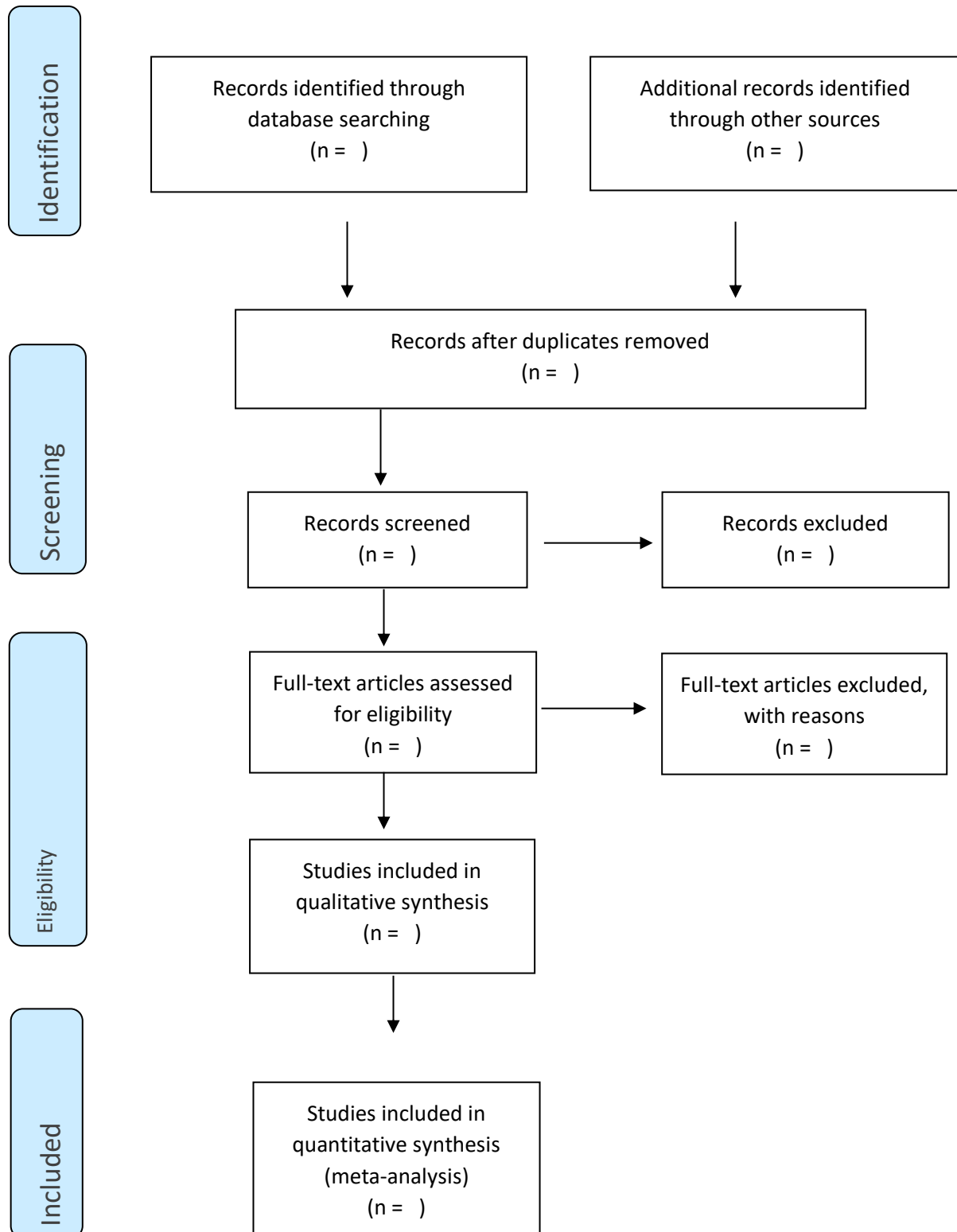
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Appendices



8.1 PRISMA 2009 Flow Diagram



8.2 Glossary and comment on condition descriptions

Glossary of terms

Additional needs:

Any need beyond that of a typically developed or healthy child

Co-morbid:

When one medical condition co-occurs with another

Complex needs:

complex needs are interpreted as when caregivers have multiple childcare responsibilities, including a higher than average care requirement, incorporating severity and type of the child or children's conditions. These additional care requirements could include overlaps on physical and non-physical conditions which may increase the complexity level experienced, identified within a cumulative complexity score framework.

Overlapping of similar terms:

When reviewing the studies for the systematic review, the term the study used was referred to throughout the review although different terminology is often being used for similar conditions. For example, McConkey et al. (2008) described the child's condition being investigated as Intellectual Disabilities, Mirsaleh et al., (2011) as Intellectual Difficulties whereas Wang et al., 2011 used the term Developmental Disabilities. These terms all refer to a child having a developmental or intellectual disability, a failure to thrive cognitively or intellectually. These terms are often replacements for increasingly outdated terminology such as mental retardation, although some older studies still used this term (Margalit et al.1992).

Conditions were combined in the Margalit et al.(1992) study to include learning difficulties, mental retardation and emotional/ behavioural conditions. These are all non-physical conditions with some variations between presentation of symptoms. Although this study had designated non-physical conditions into individual categories which were distinct from each other, the final analysis incorporated these into a broad category of Non-Physical conditions. For this study the Non-Physical category included Cognitive or learning needs, Mental health difficulties, Autism or Autistic spectrum disorder, Behaviour, emotion and social development needs and Speech language and communication disorders. These categories were utilised as they were distinct, specific and separate from each other. For the main analyses, the non-physical categories were merged to allow direct comparison between physical and non-physical conditions. When a child or children of a caregiver had both physical and non-physical conditions, they were classified as having complex needs.

8.3 Summary of measures used in coping studies including coping subscales and results

Author	Coping Measurement subscales utilised	Other measures included in study	coping results
Al-Yagon, 2011	active and avoidant coping	Coping Scale (Moos et.al), Sense of Coherence Scale (SOC), Child Behaviour Checklist (CBCL)	higher level of avoidant coping for fathers of children with LD
Barrera et al.(2004)	emotion, problem focused	Ways of Coping Questionnaire, Beck Depression Inventory, State-Trait Anxiety Inventory, SCL-90R 90, Child Behaviour Checklist	higher emotion focused for mothers of children with cancer
Dabrowska & Pisula (2010)	emotion, task and avoidance	Coping Inventory for Stressful Situations(CISS), Questionnaire of Resources and Stress (QRS)	Emotion-oriented for autism and Down Syndrome group, task-oriented for typically developed.
Hussain & Juyal, 2007	one combined score	Ways of Coping, Stress Appraisal Measure (SAM),	"better" for control
Madu & Roos (2006)	All eight subscales *	Ways of Coping, Edinburgh Postnatal Depression Scale (EPDS),	indirect link between depression and seeking social support for pre-term, accepting responsibility for full term
Margalit et al.(1992)	avoidant and active coping	Coping Scale (Moos), Family environment Scale (FES), Child Behaviour Checklist, Sense of Coherence Scale	avoidant coping for disabled group
McConkey et al. 2008	problem, emotion	Ways of Coping Revised (QRS-F), Family Functioning, Questionnaire on Resources and Stress, The General Health Questionnaire,	Coping not significant
Mirsaleh et al.(2011)	problem, emotion	Ways of Coping(WOC), Islamic Religiosity scale (IRS), NEO (NEO-FFI-S)	Coping not significant

Murphy et al.(2008)	problem, emotion	Ways of Coping (WOC), Child Behavior Checklist (CBC), Brief Symptom Inventory (BSI), Parent Involvement in Child and Household Management	Coping not significant
Author	Coping Measurement subscales utilised	Other measures included in study	coping results
Paster et al. (2009)	All eight subscales *	Ways of Coping (WOC)	seeking social support, escape avoidance, positive reappraisal for disabled group
Pisula & Kossakowska (2010)	All eight subscales *	Ways of Coping (WOC), SOC Orienting to Life Questionnaire (SOC-29)	escape avoidance used more in autism group
Rodrigue et al.(1990)	cognitive reframing, emotional expression, wish-fulfilling fantasy, self-blame, information-seeking, threat minimisation	Ways of Coping Scale (WCS) (Felton et al, 1984), Parenting Sense of Competence Scale (PSCS), Marital Adjustment Scale, Family Adaptability and Cohesion Evaluation Scale (FACES-III), Impact-on-Family Scale (IFS) Mother-child interaction Social Support Questionnaire (SSQ)	Coping not significant
Solem et al. (2011)	active, emotions, reappraisal/passive, avoidance	Coping Orientation to Problems Experienced Scale (COPE), Nijmegen Child-Rearing Situation Questionnaire (NCSQ), Social Support Scale Sense of Coherence Scale (SOC)	Coping not significant
van den Borne et al.(1999)	cognitive and behavioral avoidance, active problem solving, seeking social support.	Utrecht Coping List, Uncertainty measure, Fear Scale, Zung Depression Scale,	Coping not significant

Wang et al.(2011)	**All 15 scales	Coping Orientation to Problems Experienced Scale (COPE), Questionnaire on Resources and Stress (QRS)	acceptance, active coping, positive reinterpretation and growth, suppression of competing activities, and planning most frequently used coping strategies. autism group experienced more stress and used planning more than parents of children with other DD
*all 8 scales of the WOC are Planful Problem Solving, Seeking Social Support, Confrontive Coping, Distancing, Self-control, Escape Avoidance, Accepting Responsibility, and Positive Reappraisal. **all 15 subscales of the COPE are , positive reinterpretation and growth,mental disengagement, focus on and venting of emotions, use of instrumental social support, active coping, denial, religious coping, humor, behavioral disengagement, restraint, use of emotional social support, substance use, acceptance, suppression of competing activities, and planning			

8.4 Coping Measurement: R-COPE

R-COPE Scoring sheet

Self Help

- I take time to express my emotions
- I let my emotions show
- I try to let out my feelings
- I allow myself to show how I feel about things
- I discuss my feelings with someone
- I try to get emotional support from friends or relatives
- I talk to someone about how I feel
- I talk to someone to find out more about the situation

Approach

- I concentrate my efforts on doing something about it
- I take additional action to try to get rid of the problem
- I take direct action to get around the problem
- I do what has to be done, one step at a time
- I make a plan of action
- I try to come up with a strategy about what to do
- I think hard about what steps to take
- I try hard to prevent other things from interfering with my efforts at dealing with this

Accommodation

- I try to be optimistic in spite of what happened (changed to happens)
- I try to work on feeling positive no matter what
- I work on staying positive even when things look bad
- I get used to the idea that it happened (changed to things happen)
- I accept the reality of the fact that it happened (changed to some things happen)
- I try to see it in a different light, to make it seem more positive
- I look for something good in what is happening
- I try to identify something else I care about

Avoidance

- I say to myself "This isn't real"
- I refuse to believe that it has happened (is happening)
- I pretend that it hasn't really happened
- I admit to myself that I can't deal with it and quit trying
- I give up the attempt to get what I want
- I blame someone or something for what happened to me
- I accuse someone of causing my misfortune
- I try to forget the whole thing

Self-Punishment

- I blame myself
- I realise I brought the problem on myself
- I criticise or lecture myself
- I see that I am at the root of the problem
- I just think about my problem constantly
- I return in my head again and again to what is troubling me
- I relive the problem by dwelling on it all the time
- I brood over my problem nonstop

8.5 Cognitive Fusion Questionnaire

Cognitive Fusion Questionnaire (CFQ 13)

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it.

Use the scale below to make your choice.

never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true
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1. My thoughts cause me distress or emotional pain

2. I get so caught up in my thoughts that I am unable to do the things that I most want to do

3. Even when I am having distressing thoughts, I know that they may become less important eventually

4. I over-analyse situations to the point where it's unhelpful to me

5. I struggle with my thoughts

6. Even when I'm having upsetting thoughts, I can see that those thoughts may not be literally true

7. I get upset with myself for having certain thoughts

8. I need to control the thoughts that come into my head

9. I find it easy to view my thoughts from a different perspective

10. I tend to get very entangled in my thoughts

11. I tend to react very strongly to my thoughts

12. It's possible for me to have negative thoughts about myself and still know that I am an OK person

13. It's such a struggle to let go of upsetting thoughts even when I know that letting go would be helpful

Statements 3,6,9 and 12 are reversed

8.6 Emotion Regulation Questionnaire (ERQ)

We would like to ask you some questions about your emotional life, in particular, how you control (that is, regulate and manage) your emotions. The questions below involve two distinct aspects of your emotional life. One is your emotional experience, or what you feel like inside. The other is your emotional expression, or how you show your emotions in the way you talk, gesture, or behave. Although some of the following questions may seem similar to one another, they differ in important ways. For each item, please answer using the following scale:

1-----2-----3-----4-----5-----6-----7		
strongly disagree	neutral	strongly agree
Emotion Regulation Statements		
1 When I want to feel more positive emotion (such as joy or amusement), I change what I'm thinking about.		
2 I keep my emotions to myself.		
3 When I want to feel less negative emotion (such as sadness or anger), I change what I'm thinking about.		
4 When I am feeling positive emotions, I am careful not to express them.		
5 When I'm faced with a stressful situation, I make myself think about it in a way that helps me stay calm.		
6 I control my emotions by not expressing them.		
7 When I want to feel more positive emotion, I change the way I'm thinking about the situation.		
8 I control my emotions by changing the way I think about the situation I'm in.		
9 When I am feeling negative emotions, I make sure not to express them.		
10 When I want to feel less negative emotion, I change the way I'm thinking about the situation.		
Do not change item order, as items 1 and 3 at the beginning of the questionnaire define the terms "positive emotion" and "negative emotion".		
Scoring (no reversals)		
Reappraisal Items: 1, 3, 5, 7, 8, 10; Suppression Items: 2, 4, 6, 9.		

8.7 Adult Attachment Questionnaire (ASQ)

Confidence	
1. Overall, I am a worthwhile person.	
2. I am easier to get to know than most people.	
3. I feel confident that people will be there for me when I need them.	Avoidance (Rev)
19 I find it relatively easy to get close to other people.	Avoidance (Rev)
31. I feel confident about relating to others.	Anxiety (Rev)
37. If something is bothering me, others are generally aware and concerned	
38. I am confident that other people will like and respect me.	
33. I often worry that I do not really fit in with other people. (Rev)	Anxiety
Discomfort with Closeness	
4. I prefer to depend on myself rather than other people.	Avoidance
5. I prefer to keep to myself.	Avoidance
16. I find it hard to trust other people.	Avoidance
17. I find it difficult to depend on others.	Avoidance
23. I worry about people getting too close.	Avoidance
25. I have mixed feelings about being close to others.	
26. While I want to get close to others, I feel uneasy about it.	
34. Other people have their own problems so I don't bother them with mine.	
20. I find it easy to trust others. (Rev)	Avoidance
21. I feel comfortable depending on other people. (Rev)	Avoidance
Need for Approval	
11. It's important to me that others like me.	Anxiety
12. It's important to me to avoid doing things that others won't like.	
13. I find it hard to make a decision unless I know what other people think.	Anxiety
15. Sometimes I think I am no good at all.	Anxiety
24. I worry that I won't measure up to other people.	Anxiety
27. I wonder why people would want to be involved with me.	Anxiety
35. When I talk over my problems with others, I generally feel ashamed or foolish	
Preoccupation with Relationships	
18. I find that others are reluctant to get as close as I would like.	Anxiety
22. I worry that others won't care about me as much as I care about them.	Anxiety
28. It's very important to me to have a close relationship.	
29. I worry a lot about my relationships.	Anxiety
30. I wonder how I would cope without someone to love me.	Anxiety
32. I often feel left out or alone.	Anxiety
39. I get frustrated when others are not available when I need them.	
40. Other people often disappoint me.	
Relationships as Secondary	
6. To ask for help is to admit that you're a failure.	
7. People's worth should be judged by what they achieve.	
8. Achieving things is more important than building relationships.	Avoidance
9. Doing your best is more important than getting on with others.	Avoidance
10. If you've got a job to do, you should do it no matter who gets hurt.	Avoidance
14. My relationships with others are generally superficial.	Avoidance
36. I am too busy with other activities to put much time into relationships.	
Items marked (Rev) are reverse-scored.	
see below for instructions on how to code the two dimensions of the ASQ-SF.	
Note: Items 3, 19-21, 31, 37, and 38 must be reversed-keyed prior to computing the following two dimensional scores:	
(1) The <i>Attachment Avoidance</i> score is computed by averaging items 3-5, 8-10, 14, 16, 17, 19-21, 23, 25, 34, and 37. Higher scores reflect greater attachment avoidance.	
(2) The <i>Attachment Anxiety</i> score is computed by averaging items 11, 13, 15, 18, 22, 24, 27, 29-33, and 38. Higher scores reflect greater attachment anxiety.	

8.8 Introductory page of online survey



Emotion Regulation and Coping in Caregivers of Children with Complex needs

Hi, my name is Carol Delaney and I am studying a Research Degree at Edinburgh Napier University. My research investigates Coping and Emotional Regulation in Caregivers of Children with Complex Needs. I would like caregivers of children to take part in my research by completing this questionnaire.

The investigation is comparing caregivers of typically developed children with caregivers of children with physical, psychological or more complex needs. The additional care requirements include physical or medical difficulties such as epilepsy, cerebral palsy, diabetes or cancer and cognitive and developmental demands such as learning difficulties and Autism or ASD as well as sensory impairment or mental health difficulties such as depression or eating disorders. There is an opportunity to comment if you are awaiting diagnosis, prefer not to label your child or add anything relevant to your situation.

As it is important to compare differences I would also like to hear from you if you are a caregiver of a child or children with no additional physical or psychological demands.

To take part in this survey you need to be

- 1) a caregiver of any children under the age of 18
and
- 2) a resident of UK or ROI

The survey should take about 20 minutes to complete and to ensure that you are comfortable taking part in the research great care has been taken throughout the questionnaire. You will have the opportunity to decline to answer any question you do not wish to respond to and there is an exit survey button on every page. In case any part of the survey has triggered an unintentional emotional response, contact details for The Samaritans, Parentline and Contact a Family have been provided at the end of the survey.

You will be asked to respond to questions and statements relating to coping strategies, attachment styles and support systems you may use when caring for your child or children. There will also be questions about you and how you manage your emotions. If you do have a child or children that has additional caring requirements, you will also be asked about the type and severity of the need.

If you would prefer to respond on a paper version of this survey, please indicate below by providing your name and address and I will post the survey and a stamped addressed return envelope to you. You can then select next at the bottom of the page then choose "exit the survey" at the top right of the next page. If you are happy to participate on this electronic version, please ignore the box below and continue on to the information page.

8.9 Second page with information regarding the online survey



Emotion Regulation and Coping in Caregivers of Children with Complex needs

Information Page

The information given is completely confidential and anonymous and will be used for research purposes only. By completing this survey you are giving permission for your responses to be used as part of this investigation. If you decide at any time during the survey that you don't wish to continue you can withdraw by clicking on the "Exit Survey" button at the top right of the screen.

On completion of the questionnaire, you will be asked to provide a memorable word or phrase so that if you wish to withdraw from participation after completion, I will be able to identify and delete your data. If the findings are published, confidentiality and anonymity will continue to be assured.

If you wish a summary of the findings, contact details will be provided at the end of the survey. If you wish to ask me any questions before taking part in this survey, send an email to me, Carol Delaney, at 09001507@live.napier.ac.uk. My project Supervisor is Professor Thanos Karatzias and he can be contacted on Tel. 0131 455 5345 or by Email at t.karatzias@napier.ac.uk

If you would like to contact Edinburgh Napier University directly, the Independent advisor is Barbara Neades, Senior lecturer, Convenor of Ethical Approval Group, Faculty of Health, Life & Social Sciences, 0131 455 5315, email b.neades@napier.ac.uk

If you fully understand what I have explained and are happy to participate in this study, please select the Yes option at the bottom of this page.

Many thanks

***2. I agree to participate in this survey as outlined above**

☐ Yes

☐ No

Prev Next

8.10 Information on survey about right to withdraw and options for contact

[Exit this survey](#)



Emotion Regulation and Coping in Caregivers of Children with Complex needs

Time is precious as a caregiver so I really appreciate you taking part in my survey. The survey is being used to understand more about how emotion and cognition (thinking about things) influence coping and attachments styles when caregivers are under stress. This has been done by comparing caregivers with different physical and psychological demands with that of caregivers of children that are typically developed or don't have health conditions.

The statements you answered are associated with coping, attachment, emotional resources and Cognitive Fusion. It may be that an unintentional emotional response has been triggered by a question in this survey. If you have been affected in this way, support can be sought through organisations such as The Samaritans on www.samaritans.org 08457 90 90 90 or ROI 1850 60 90 90. Parentline can be reached at familylives.org.uk/how-we-can-help or 0808 800 2222. For caregivers of children with disabilities or health conditions, Contact a family has a list of services provided at [http://www.cafamily.org.uk/what-we-do/our-services-\(1\)/](http://www.cafamily.org.uk/what-we-do/our-services-(1)/), these is also a helpline number open Monday to Friday 9:30 to 5pm on 0808 808 3555 and email helpline@cafamily.org.uk

The anonymous data will only be accessible to myself and members of the research team at Edinburgh Napier University. If the findings are published, confidentiality and anonymity is assured. If you would like to ask me more details about this survey or would like a summary of the findings, please email me at 09001507@live.napier.ac.uk. My project Supervisor is Professor Thanos Karatzias and he can be contacted on Tel. 0131 455 5345 or by Email at t.karatzias@napier.ac.uk

If you would like to contact Edinburgh Napier University's Independent Advisor regarding this survey, please contact: Barbara Neades, Senior Lecturer, Convenor of Ethical Approval Group, Faculty of Health, Life & Social Sciences 0131 455 5315, b.neades@napier.ac.uk

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8.11 Final page of survey with reminder of right to withdraw and process.

***55. Confidentiality and anonymity is assured however after completion of this questionnaire, you may decide you no longer wish your information to be used for research purposes. In order to allow this option for all participants, I need to identify your data if deletion is requested.**

For this purpose only, please type a memorable word or phrase in the box below. You can then email me on 09001507@live.napier.ac.uk and quote the word you provided. This will allow me to identify and delete your information.

This survey has now been extended until 31st August 2013. You will be able to withdraw your data until 1st September 2013 as after this time the anonymous data will be fully incorporated in the final thesis.

Adding your chosen word or phrase will complete this survey. If you have decided that you no longer wish to participate, please use the exit survey button at the top right of this page instead and your responses will not be included in the research.

☐ Please type your memorable word or phrase in this box:

☐ Memorable word or phrase

56. Please use the box below for any comments or remarks. If you want a summary of the findings, please use this box to leave your email address.

Thanks you once again for taking the time to take part in my study.

Carol Delaney

Prev Done
