

Doctorate in Educational Psychology (DEdPsy)
Professional Training Programme

**An Interpretative Phenomenological Analysis of adolescent siblings'
experiences of aggression by a brother with Autism Spectrum Disorder,
and their perceptions of their coping processes**

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Thesis

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Summary

This thesis consists of three parts: a literature review, an empirical paper and research reflective summary. In response to a critical examination of the literature it is suggested that research to date has not explored in depth how siblings experience and cope with aggression by their brother or sister with ASD. This study seeks to address this gap in the literature.

Part one: literature review

The literature review explores and critically discusses a number of areas. The construct of Autism Spectrum Disorder (ASD) is explored and a critical discussion of the epidemiological research examining the prevalence of ASD is undertaken. The rationale for identifying and addressing the needs of siblings in relation to their experiences of a brother or sister with ASD is placed in the context of agendas and policies in the United Kingdom (UK). A critical examination of the empirical literature of the emotional, behavioural and psychosocial adjustment of siblings of children with Autism Spectrum Disorder (ASD) is provided. Emerging from this body of literature is the finding that the presence of aggression in a brother or sister with ASD places their sibling at risk for a range of adjustment difficulties. The epidemiological literature of the prevalence of aggression in individuals with ASD is critically examined and causes of the aggression in this population identified. A critical review of the quantitative and qualitative empirical research relating to siblings' experiences of aggression by a brother or sister with ASD is undertaken. A paucity of literature is identified. A critical review of the theoretical literature on coping is given. The rationale of the current study in relation to exploring the subjective perceptions of siblings' lived experience and siblings' perceived effective coping processes is provided.

Part two: empirical paper

Part two is a qualitative empirical research study that aimed to gain an in-depth understanding of how siblings make sense and construct meaning from their experience of aggression by their brother with ASD. It aimed also to develop an in-depth understanding of siblings' experiences and perceptions of their effective coping processes in attempting to adapt to the aggression. The study employed Interpretative Phenomenological Analysis as a methodology to explore the study's aims. Six adolescent siblings aged 14-17 years participated in the study and semi-structured interviews were used to explore their perceptions. Four superordinate themes were identified: a threatened and disempowered self, gaining a sense of control, interpersonal coping and making and changing meaning. Superordinate and subthemes are discussed in relation to the existing empirical literature and psychological theories. The contribution to knowledge, future research, limitations and applications to the role of the educational psychologist are discussed.

Part three: research reflective summary

Part three is a reflective summary of the research study and consists of two parts. The first section provides a critical account of the research methodology. Methodological decisions are justified and critically considered. The second section is concerned with the study's contribution to knowledge.

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Part two: empirical paper

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Table of Abbreviations

Autistic Spectrum Disorder (ASD)

Broad Autism Phenotype (BAP)

Educational Psychologist (EP)

Interpretative Phenomenological Analysis (IPA)

Pervasive Developmental Disorder not otherwise specified (PDD-NOS)

The Diagnostic and Statistical Manual of Mental Disorders V (DSM-V)

The International Classification of Diseases 10 (ICD-10)

United Kingdom (UK)

Part one: literature review

(word count 9,876)

1.0 Introduction to the literature review

The following literature review will critically discuss a number of areas. The rationale for the current study emerges through a critical discussion of the literature presented over the course of the review. The first section will introduce the construct of Autism Spectrum Disorder (ASD). This is provided to identify the types of behaviours that siblings of children with ASD are likely to be exposed to. Furthermore, the heterogeneous nature of ASD is introduced and the changeable nature of the presentation across developmental stages. This illuminates the suggestion of the likelihood of the variability in the experiences both across and within siblings of children with ASD. The review then focuses on the epidemiological literature of ASD to examine the scope of the condition. Legislation, policies and agendas relating to ASD in the United Kingdom (UK) are discussed. Emerging from this discussion is that identifying and addressing siblings' needs in relation to having a brother or sister with ASD, is placed on the agenda at a strategic level. A critical discussion is presented of the empirical literature relating to the emotional, behavioural and psychosocial 'adjustment' of siblings of children with ASD. This focuses on the inconsistencies identified in sibling adjustment outcomes. Emerging from this literature is the finding that the presence of aggression in children with ASD is associated with adjustment difficulties in siblings. The epidemiological literature examining the prevalence of aggression in individuals with ASD is reviewed and empirical research exploring the causes of aggression in this population is discussed. A critical review of the quantitative and qualitative empirical literature relating to siblings' experiences of aggression by a brother or sister with ASD is undertaken. It is identified that a paucity of empirical research is available and key gaps in this body of research are identified. A review of the theoretical perspectives on coping is provided. The rationale for the study is presented.

1.1 Searches

A number of electronic databases were used to inform the literature review including PsycInfo, PubMed, Google Scholar and Science Direct. The keywords used were: siblings, Autism Spectrum Disorder (ASD), autism, aggression, coping, adjustment.

Key sources included recent reference textbooks relating to coping. Internet searches were employed to review relevant government policy and guidelines. Searches were completed in March 2015.

1.2 Definition of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) refers to a pervasive, lifelong, developmental disorder that primarily affects social understanding and functioning but manifests itself differently across the lifespan (Lord & Spence, 2006). Since the original description of 'childhood autism' by Kanner in the 1940's a number of different diagnoses and terminology have been presented within the literature. These have included Childhood Autism, Atypical Autism, ASD, Autism Spectrum Disorder, Autism Spectrum Conditions, Pervasive Developmental Disorder not otherwise specified (PDD-NOS) and Asperger Syndrome.

The current criteria for diagnosis of ASD are based upon two main classification systems: 1) The International Classification of Diseases 10 (ICD-10) (World Health Organisation, 2010) and, 2) The Diagnostic and Statistical Manual of Mental Disorders V (DSM-V) (American Psychiatric Association, 2013). In the United Kingdom (UK), the ICD-10 is predominantly used (Kent, Carrington, Le Couteur, Gould, Wing, Maljaars, Noens, van Berckelaer-Onnes & Latham, 2013). The two classification systems present different diagnostic categories, each adopts criteria for diagnosis relating to core impairments in observable behaviour in the following domains: reciprocal social interaction, reciprocal social communication and restrictive interests, and rigid and repetitive behaviours. In addition, both classification systems acknowledge differences in the severity of impairment across the different core domains. The severity of impairment range from mild to severe, and are categorised according to the impact the impairment has on an individual's functioning (American Psychiatric Association, 2013; World Health Organisation, 2010).

Research highlights that core impairments appear to manifest differently across the lifespan. For example, Leekam, Prior & Uljarevic (2011) report in the early years children appear to express rigid and repetitive behaviours though motor movements such as hand flapping and banging. In comparison, these restrictive and repetitive behaviours appear to become more cognitive in presentation in late childhood such as

talking about very narrow subjects of interest (Leekam et al. 2011). It is suggested these presentations also are likely to be influenced by a child's language and cognitive ability. In addition, core impairments in social interaction and social communication also have been found to present in a multitude of ways, and change through the lifespan. For example, in infancy, these may include a lack of reduced responses to joint attention requests (Sullivan, Finelli, Marvin, Garrett-Mayer, Bauman & Landa, 2007) and limited initiations of joint attention (Dawson, Toth, Abbott, Osterling, Munson, Estes & Liaw, 2004). During later childhood, difficulties may include sustaining reciprocal conversations and increased conversation breakdown (Paul, Miles, Cicchetti, Sparrow, Klin & Volkmar, 2004).

In addition to the core impairments, co-morbid difficulties and conditions are also prevalent among individuals who are diagnosed with ASD. Although discrepancies in the epidemiological literature exist, cognitive impairments (defined as an intelligence quotient of less than 70) co-vary highly with ASD diagnosis (Matson & Shoemaker, 2009). In a narrative review, Johnson and Meyers (2007) identify that pre 1990 estimates of prevalence of cognitive impairment in individuals with ASD were around 90% yet post 2000 this prevalence reduced to 50%. The researchers discussed a possible explanation for the decrease in prevalence as resulting from improved methods in testing intelligence in this population. In addition, meta-analytic evidence demonstrates that 40% of children and young people with ASD also likely to suffer from an anxiety disorder (van Steelsen, Bögels & Perrin, 2011). Furthermore, narrative reviews of epidemiology research investigating the prevalence of aggression in individuals with ASD reveal prevalence of 6-68% (Hill, Zuckerman, Hagen, Kriz, Duvall, Santen, Nigg, Fair & Fombonne, 2014; Farmer & Aman, 2011).

The preceding section has highlighted the notion of heterogeneity in presentation of ASD. This is highlighted through differential severity in core impairments, changing presentations across the life course and the range of comorbidities individuals with ASD may experience.

1.3 Epidemiology of Autism Spectrum Disorder

Epidemiological research suggests that, internationally, the number of children receiving a diagnosis of autism and ASD has risen dramatically (Matson & Kozlowski, 2011).

Early epidemiological research suggested that ASD was a relatively rare condition with estimated prevalence rates of 3-5 per 10,000 within the general population (Lotter, 1966; Brask, 1972; Wing, Yeates, Brierly & Gould, 1976; Rutter, 1978; Wing & Gould, 1979). Fombonne (2005) noted the prevalence of ASD diagnosis appeared to remain relatively stable until the 1990's (3.26-4.8 per 10,000), after which, a dramatic rise was apparent (21-46 per 10,000). More recent epidemiological research conducted in the UK has revealed prevalence rates as high as 38.9 per 10,000 (Baird, Simonoff, Pickles, Chandler, Loucas & Meldrum, 2006) and 94-99 per 10,000 (Baron-Cohen, Scott, Williams, Bolton, Matthews & Brayne, 2009).

The marked increase in prevalence rates of ASD diagnosis has instigated significant debate over what has contributed to the rise (Matson & Kozlowski, 2011; King, Jenner & Spratt, 2008; Wazana, Bresnahan & Kline, 2007, Chakrabarti & Fombonne; 2005; Nicholas, Charles, Carpenter, 2005; Williams, Mellis & Peat, 2005; Wing & Potter, 2002). A number of critiques have emerged in an attempt to account for this observed variability. One methodological critique focuses on the use of different sampling procedures across studies. Fombonne Simmons, Ford, Meltzer & Goodman (2001) suggest that although some research has employed random sampling procedures most have utilised convenience sampling recruiting participants from localised geographical areas. They argue this is problematic because although there should be no prior reason to assume differences in actual prevalence of ASD across locations it could be that diagnosis of ASD may be different across geographical areas. Therefore, they suggest that variation in prevalence of ASD diagnosis may reflect differences in the sampling procedures employed. Alternative methodological explanations suggest the rise could be due to widening diagnostic criteria over time (Shattuck, 2006). Moreover, increased awareness of ASD in various health practitioners, different personnel within education and in parents may have contributed to the rise in prevalence of diagnosis (Elsabbagh, Divan, Koh, Kauchali, Marcin, Montiel-Nava, Patel, Paula, Wang, Yasamy & Fombonne, 2012). There is also the recognition that the rise may reflect a true increase in actual prevalence of ASD (Herbert, 2010).

This section has examined the estimated prevalence of ASD diagnosis in the general population. A rise in prevalence of ASD diagnosis can be observed over time. Importantly, literature has examined the possible reasons for the rise in prevalence.

However, what is evident is that, currently within the United Kingdom (UK), a large number of children, young people, adults and their parents and siblings are affected by ASD.

1.4 Legislation, policies and agendas relating to Autism Spectrum Disorder in the United Kingdom

In the UK a range of statutory acts, policies, agendas and guidelines provide strategic direction for local education, health and social care authorities, to address the needs of people with ASD from childhood through to adulthood. A selection of these include the Autism Act (2009), Fulfilling and Rewarding Lives: The Autism Strategy for Adults in England (2010), The Autistic Spectrum Disorder: Strategic Action Plan for Wales (2008), Autism: The Management and Support of Children and Young People on the Autism Spectrum (National Institute for Clinical Excellence, 2013) and Autism Diagnosis in Children and Young People: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum (National Institute for Clinical excellence, 2011). These documents address a range of areas including assessment, intervention, commissioning of services and advocate the notion of multidisciplinary working to support and address the needs of individuals with ASD.

In addition, some of these agendas and guidelines also recognise the impact of individuals with ASD on family members (Welsh Government, 2008; National Institute, 2013). For example, the Autistic Spectrum Disorder: Strategic Action Plan for Wales (2008) identifies parents, carers and also, specifically, siblings as having a range of needs associated with their sibling with ASD. Moreover, the Autistic Spectrum Disorder: Strategic Action Plan places a responsibility on local services across health, social care and education to identify and address them. It could be argued that this recognition is in response to a large body of empirical research documenting both siblings and parents of children with ASD are at risk for a range of mental health, behavioural, emotional and psychosocial adjustment difficulties (Hayes & Watson, 2013; Green, 2013; Smith & Elder, 2010). The importance of identifying needs and support for siblings of children with ASD is placed firmly on governmental agendas in Wales (Welsh Government, 2008).

Theoretically, the reciprocal influence of family members on one another within the unit is implicated from a family systems theory perspective (Dallos & Draper, 2010; Trivette, Dunst & Hamby, 2010). Empirical interest in siblings of children with ASD was generated by the seminal paper by McHale, Sloan and Simeonsson (1986). It was identified that siblings with a brother or sister with ASD exhibited higher stress levels compared to 1) siblings of children with other difficulties and, 2) siblings of children who were 'typically' developing. The next section will critically review the empirical research of the 'adjustment' of siblings of children with ASD.

1.5 Critical review: empirical research of the adjustment of siblings of children with ASD

A large body of research has examined the 'adjustment' of siblings of a child with ASD. Review of this literature reveals that siblings' 'adjustment' typically has been operationalised as behavioural (externalising), emotional (internalising) or psychosocial difficulties and has been explored quantitatively adopting a cross sectional methodology. As highlighted above, a large number of studies identify that siblings of children with ASD show a range of internalising and externalising adjustment difficulties in comparison to controls (Griffith, Hastings & Petalas, 2013; Shivers, Disenroth & Taylor, 2013; Constantino, Lajonchere, Lutz, Gray, Abbacchi & McKenna, 2006; Giallo & Gavidia-Payne, 2006; Ross & Cuskelly, 2006; Hastings 2003; Verte, Roeyers & Buysee, 2003; Freeman, 2000; Gold, 1993). However, review of this empirical research by the current researcher, and a number of narrative reviews of this literature, suggest that siblings of children with ASD are not always at risk of adjustment difficulties and across studies there are large inconsistencies across siblings' adjustment outcomes (Green, 2013; Meaden, Stoner & Angell, 2010; Smith & Elder, 2010). In light of this, a key theoretical and clinical goal has been to understand the reasons for the differences across siblings' adjustment outcomes (Green, 2013).

A number of methodological issues across the empirical studies have been suggested that may account for some of the observed variability. Firstly, Pollard, McNamara, Freedman, Kotchick (2013) propose the variability in siblings' adjustment outcomes may reflect the heterogeneous definitions and measures of 'adjustment' employed across studies. Secondly, Petalas, Hastings, Nash, Lloyd and Dowey (2009) argue some of the variation observed in the adjustment of siblings of children with ASD could be due,

in part, to individual studies employing different comparison groups. Indeed, some studies employ comparison groups of siblings of children with 'other developmental difficulties', some of children who are 'typically developing' and some compare against normative samples. To further support Petalas et als. (2009) proposition, meta-analytic evidence reveals that comparisons with normative samples estimate higher levels of psychological problems than comparisons with comparison groups (Rossiter and Sharpe, 2001). In addition, there appears to be great heterogeneity in the ages of siblings of children with ASD included across studies. From a developmental perspective, the psychosocial and cognitive development of children in early and middle childhood and in adolescence is very different (Erikson, 1963). Indeed, there are many factors relating to the cognitive development, identity development and moral development of siblings of children with ASD at different ages that could potentially moderate and mediate adjustment.

Aside from methodological critiques, researchers have identified a range of variables across a range of ecological systems levels that are associated with the adjustment of siblings of children with ASD using cross sectional and longitudinal designs.

- 1) Increased parental stress and parental mental health difficulties have been associated with increased behavioural and emotional adjustment difficulties in siblings of children with ASD (Davis & Carter 2008; Hastings & Brown, 2002).
- 2) Parental satisfaction in their ability to care for their child with ASD is correlated to increased siblings' adjustment (Hesse, Danko & Budd, 2013).
- 3) Family connectedness (the extent to which parents and children participated in shared family activities), parent agreement (the extent to which parents agreed on key family issues, including parenting, childcare, and the allocation of work and domestic responsibilities) and child marital impact (the extent to which the parents viewed the child with autism as bringing the parents closer together) are all found to be correlated to increased sibling emotional and behavioural adjustment (Benson & Karloff, 2008).
- 4) The presence of the Broad Autism Phenotype (BAP) in siblings of children with ASD is correlated with their increased adjustment difficulties (Petalas, Hastings, Nash, Hall, Joannidi and Dowey, 2012; Meyers, Ingersoll & Hambrick, 2011). The BAP describes impairments in social communication, language, stereotyped behaviours, cognition, and emotional experience qualitatively similar to ASD, but,

not reaching criteria for diagnosis (e.g., Bolton, Pickles, Murphy & Rutter, 1998). The presence of BAP further supports the extensive body of literature that acknowledges a genetic aetiology of ASD (Sasson, Lam, Parlier, Daniels & Piven, 2013; Losh, Childress, Lam & Piven, 2009; Gerds & Bernier, 2011).

- 5) The presence of aggression and behaviour problems in the child with ASD is associated with increased sibling adjustment difficulties (Pollard, Barry, Freedman & Kotchick, 2013; Petalas et al., 2009; Benson & Karloff, 2008; Hastings, 2007).

The above findings contribute to the evidence base by identifying a range of both risk and protective factors for the 'adjustment' of siblings of children with ASD. However, the quantitative based siblings' adjustment literature has not attempted to explore what siblings themselves deem to be pertinent regarding their own experiences of having a brother or sister with ASD. Indeed, only a small body of qualitative research has examined the perceptions of siblings living with a brother or sister with ASD. Emerging from this literature is that siblings themselves perceive aggression by a brother or sister with ASD to be particularly stressful (Petalas, Hastings, Nash, Kelly & Dowey, 2012; Benderix & Sivberg, 2007; Mascha & Bucher, 2006). In light of these findings, it is suggested that further exploration is warranted. Indeed, Hodgetts, Nicholas & Zwaigenbaum (2013) identify that there is a paucity of empirical research that has attempted to explore how families experience, and are affected by, the aggression of a child with ASD. The empirical research surrounding siblings of children with ASD who experience aggression will be critically reviewed below. First, a brief review of what is known regarding aggression in children with ASD will be provided.

1.6 Aggression in individuals with ASD: prevalence and causes

There are currently no nosological classifications of aggression (Farmer & Aman, 2011). However, factor analysis has distinguished between form and function (Connor, 2002). Form defines the type of aggression between physical (towards people, animal and property), emotional (verbal) or social aggression (Tucker, Gundy, Wiesen-Martin, Sharp, Rebellon & Stracsuzzi, 2014). Function focuses on the motivation of the aggressor (Card & Little, 2006).

Epidemiological research that has examined the prevalence of physical and verbal ('form') aggression in individuals with ASD suggest aggression is highly prevalent. Indeed, a particularly large scale study involving 1038 4-17 year olds with ASD adopting a standardised measure of aggression revealed a prevalence of 68% (Kanne & Mazurek, 2011). A real limitation of this epidemiology research is the lack of specific information derived about the aggression. For example, who or what the aggression is directed at, and what specific acts of aggression are involved. Indeed, Maurek, Kanne and Wodka (2013) propose the development of a multidimensional psychometric measure of aggression is required specifically for the ASD population including subtypes, frequencies and targets of aggression to give a more nuanced understanding of aggression in individuals with ASD.

Definitions of aggression that incorporate the 'function' typically describe aggression as verbal or non-verbal behaviour with the intention to physically or emotionally harm other people or objects (Hartup, 2005). Central to this definition is the notion of intent, which, most researchers agree is the necessary condition for aggression (Farmer & Aman, 2011). However, the issue of intent becomes particularly pertinent when considering individuals with ASD. Indeed, a range of empirical research suggests aggression in individuals with ASD may be related to a reduced capacity rather than intentionally causing harm. For example, Pouw, Rieffe, Oosterveld, Huskens and Stockmann (2013) identified that decreased cognitive empathy in children with ASD was positively associated with aggression. This finding suggests that the expression of aggression in individuals with ASD may be related to deficits in cognitive empathy (e.g. Theory of Mind) related to core impairments of the diagnosis. In addition, Mazefsky, Herrington, Siegel, Scarpa, Maddox, Scahill and White (2013) suggest that individuals with ASD may have a reduced capacity to manage aggression due to difficulties with emotional regulation skills. Indeed, individuals with ASD have also been found to show difficulties with assessing and labelling their own emotions (i.e. alexithymia, Berthhoz & Hill, 2005; Fitzgerald & Molyneux, 2004). Evidence from neuro-anatomical studies involving the amygdala suggests that individuals with ASD have problems with the perception and regulation of emotions (Adolphs, Sears, & Piven, 2001; Fine, Lumsden, & Blair, 2001). Furthermore, individuals with ASDs have been found to have a reduced capacity to engage in emotional regulation strategies such as cognitive reappraisal and distraction

in comparison to controls (Samson, Huber & Gross, 2012; Konstantareas & Stewart, 2006).

The findings discussed in this section suggest that siblings of children with ASD may very well be exposed to aggression. Furthermore in light of the findings that aggression in individuals with ASD may be a function of a reduced capacity relating to a lack of cognitive empathy and/or reduced emotional regulation skills, in what ways if any, does this affect their siblings' experience of aggression? As highlighted previously, Hodgetts et al. (2013) identify there is a paucity of empirical research that explores the impact on family members and in particular the siblings of the aggression by children with ASD. It has been identified above in this review that siblings themselves perceive the aggression to be particularly problematic and, furthermore, the presence of aggression places siblings at risk for a range of adjustment difficulties. However, the subsequent section will critically review the empirical literature exploring siblings and the experience of aggression by a brother or sister with ASD to identify gaps in the current evidence base.

1.7 Critical review: empirical research exploring siblings experiencing aggression by a brother or sister with Autism Spectrum Disorder

Previous research on siblings experiencing aggression by a brother/sister with ASD has highlighted largely negative experiences and outcomes. As noted above, a number of studies identify the presence of aggression in children with ASD is associated with increased behavioural (externalising) and emotional (anxious, withdrawn) adjustment difficulties for their siblings (Pollard, Barry, Freedman & Kotchick, 2013; Petalas et al., 2012; Benson & Karloff, 2008; Hastings, 2007). Predominantly, these studies adopted a cross sectional quantitative design which precludes the assessment of causality and establishing if siblings' adjustment difficulties continued over the longer term. However, Benson and Karloff (2008) were able to establish directionality using a longitudinal design by establishing temporal precedence. They revealed the presence of aggression in a child with ASD predicted their siblings internalising adjustment difficulties over two years.

Whilst these studies demonstrate important findings a limitation of this body of research should be noted. In all of these studies, the presence of aggression is measured by a

'total behaviour problem' score which includes other subscales such as hyperactivity and anxiousness. Therefore, it could be argued it is difficult to separate specifically what 'total behaviour problems' may be associated with siblings' adjustment difficulties. However, Pollard et al. (2013) discuss the proposition that the presence of aggression is likely to affect siblings' adjustment difficulties. Indeed, this suggestion appears very plausible when considering extant literature. For example, an enormous body of literature documents the negative outcomes in children who both witness and experience aggression. Meta-analytic evidence demonstrates the negative psychosocial outcomes in children who witness inter-parental violence across 118 studies ($d=-0.29$) (Kitzmann, Gaylord, Holt & Kenny, 2003). Additionally, meta-analytic evidence reveals that victimisation through peer aggression predicts internalising difficulties in children based on longitudinal studies involving 13,978 children (Reijntjes, Kamphuis, Prinzie & Telch, 2010). Furthermore, in a meta-analysis including 39, 667 children and adolescents, Fowler, Tompsett, Braciszewski, Jacques-Tiura and Baltes (2009) revealed that community violence was found to have effects on children and adolescents presenting with posttraumatic stress disorder (PTSD), externalizing problems and internalizing symptoms ($d=0.79$, $d=0.63$ and $d=0.45$ respectively). Despite the suggested problem with specificity in the empirical research it can be established the *presence* of aggression in children with ASD is associated with negative adjustment outcomes in their siblings. However, what these quantitative studies do not answer are the possible underpinning processes involved with siblings' adjustment difficulties when they experience aggression by a brother or sister with ASD.

In addition to this, a small number of qualitative research studies highlight negative influences on siblings through their experience of aggression by a brother/sister with ASD. Mascha and Bucher (2006) identified the presence of aggression is the stressor of concern most pertinent to siblings surrounding their experience of living with a brother/sister with ASD. It is suggested this is particularly important because siblings themselves suggest their experience of aggression is deemed particularly stressful in relation to living with a brother/sister with ASD. Additional insight has been offered by Benderix & Sivberg (2007) who revealed that siblings felt anxious and unsafe in their homes as a result of the aggression by their brother/sister with ASD. Furthermore, aggression is perceived by siblings to be unpredictable (Petalas, Hastings, Nash, Reilly & Dowey, 2012; Benderix & Sivberg, 2007).

Yet, as a body of research these qualitative studies focused on a descriptive rather than a latent or explanatory level. Although findings such as siblings feeling unsafe and anxious in their homes may highlight possible processes underpinning their negative perception, it is suggested these findings are preliminary. It is suggested these studies have provided little knowledge and it remains unclear why or how siblings perceive they are particularly affected negatively by the aggression. An additional limitation of both the quantitative and qualitative studies discussed is no description was provided regarding the frequency or severity of aggression the siblings were exposed to. It is argued that the frequency of exposure to aggression is likely to affect the sibling experience. Indeed, Sinclair, Pettit, Harrist and Dodge (1994) demonstrated that increased frequency of peer aggression was associated with increased behavioural difficulties in children. It is suggested this methodological limitation should be accounted for in future research by documenting the frequency of siblings' exposure to aggression by a brother/sister with ASD. Moreover, it is suggested that further in-depth exploration of siblings' perceptions and how they construct and make meaning of their experience with aggression may provide further insight into the underlying processes that may be contributing to the adjustment difficulties as described above.

The empirical research critically reviewed above demonstrates negative outcomes for siblings who experience aggression by their brother or sister with ASD. It is argued that the negative outcomes identified in the current evidence base have created a socially constructed knowledge base which pathologises siblings who experience aggression by a brother/sister with ASD. However, drawing on theoretical perspectives on coping, individuals are perceived not to be passive recipients of adversity but will show agency and will make dynamic adjustments to attempt to overcome adversity (Folkman, 2011). Theoretically, coping has been hypothesised as a mediator between adversity and adaptation (Pakenham, 2011; Park, 2011). In line with the upsurge of the positive psychology movement (Seligman & Csikszentmihalyi, 2000) across the social sciences, it is suggested exploring the construct of coping will provide a shift from a current predominant focus on pathology to understanding the processes involved with how siblings may adapt to their experiences with aggression. To the current author's knowledge only one study has explored the coping strategies adopted by siblings in response to aggression by a brother/sister with ASD.

Ross and Cuskelly (2006) quantitatively investigated the perceptions of 25 8-15 year old siblings regarding the frequency and perceived effectiveness of their use of coping strategies in response to aggression by their brother/sister with ASD. The most common coping strategies used in relation to aggression were emotional regulation and wishful thinking, both reported by 91% of the children. These were followed by social withdrawal (86%), distraction (81%), problem solving (71%), social support (62%), resignation (57%), cognitive restructuring (48%), blaming others (24%), and self-criticism (10%). The proportion of children who perceived specific coping strategies to be effective were as follows: emotional regulation (84%), wishful thinking (84%) social withdrawal (89%) distraction (100%), problem solving (93%), social support (92%), resignation (58%), cognitive restructuring (100%), blaming others (60%), and self-criticism (50%). However, the quantitative methodology employed in their study is suggested to have prevented an in-depth exploration of why and how siblings perceived these strategies to be effective. In addition, the questionnaire based methodology employed precludes siblings articulating other strategies they may have employed which were not included in the questionnaire. Furthermore, the cross sectional methodology adopted by Ross and Cuskelly (2006) precluded an appreciation of a process oriented examination of siblings perceived effective coping strategies regarding if, how and why they perceived their coping strategies to change over time. In light of this, it is argued further research is warranted investigating siblings' perceptions of their effective coping processes in response to the aggression by their brother/sister with ASD. It is suggested an in-depth exploration of how siblings perceive they cope with and adapt to the aggression they experience will contribute to the evidence base in understanding how siblings, from their own perspective, may be supported with their experiences of aggression. To understand how siblings may perceive the coping processes involved to manage the aggression they experience it is suggested it is helpful to critically review the theoretical literature on coping which is considered in the subsequent section.

1.8 Critical review: theoretical perspectives of coping

1.8.1 Introduction

Coping is a very broad multidimensional concept with a long history (Carver & Conner-Smith, 2010). The construct of coping is complex because a plethora of theories from a

variety of perspectives pervade the literature (Aldwin, 2011). A unifying theme found within these theoretical perspectives purport the assumption that an individual's coping strategies or resources can mediate the link between stressors and adversities and psychological and physical health (Folkman, 2011). Zautra & Reich (2012) highlight how coping theory has broadened significantly in recent years and has been substantially influenced by the paradigm shift of the positive psychology movement across the social sciences. This new orientation has a distinctive focus both conceptually and empirically on the positive (Seligman and Csikszentmihalyi, 2000). Based on these suggestions, coping theory may provide a useful framework for understanding processes involved in positive adaptation to adversity. Furthermore, Folkman (2011) emphasises that coping processes may be particularly relevant because they can be targeted for intervention. Evidence for this proposition is highlighted by a number of meta-analyses of intervention studies documenting the salutary benefits for wellbeing of developing additional or different coping strategies (Bolier, Haverman, Westerhof, Riper, Filip, Smit & Bohlmeijer, 2013; Kraag, Zeegers, Kok, Hosman & Abu-Saad, 2006).

Yet despite the attractiveness of the construct of coping, as highlighted above, the construct of coping is complex. The many different theories suggest a plethora of different processes involved in adaptation to adversities, and, many overlapping conceptualisations can be seen. This complexity is further compounded by the plethora of different terminologies across perspectives, some theories focus at the micro level suggested very specific processes involved with adaptation, some are more of a generic and heuristic model and do not propose particular hypotheses regarding adaptation. In addition, a review of the literature indicates that different theoretical perspectives and models emanate from a diverse range of 'stressor types'. All of these issues together pose challenges to synthesis of the literature. The focus of the following section will attempt to synthesise the coping literature by focusing on what theories and models purport about the processes involved with adaptation to adversities and stressors. No area has been specifically excluded however interested readers are invited to see the reference texts of Folkman (2011) and Rice (2012) in addition Frydenberg's (2014) critical discussion paper.

1.8.2 Psychoanalytic perspectives of coping

The psychodynamic perspective offered the first conceptualisation of how individuals attempt to adapt to adversity (Aldwin, 2007). Within this framework, the term 'defense mechanisms' was coined to describe the processes individuals engage in to deal with distress. The function of the various defense mechanisms was conceived as unconscious intra-psychoic efforts to alter the individual's perceptions, to protect the person from anxiety and distress created either by an external event or a disrupted internal state (Kramer, 2010). Examples of major defense mechanisms proposed by Freud (1966) include repression, dissociation and isolation. However, Vaillant (1994) proposed a much larger repertoire of defenses and, importantly, extended previous models by ordering defenses hierarchically. This hierarchical model presents the idea that certain defenses are better than others or, put in another way, are more 'adaptive'. Four levels of 'adaptive' defenses were delineated: psychotic (e.g. denial, distortion of reality), immature (e.g. acting out, dissociation), neurotic (e.g. intellectualization, repression), and mature (e.g. humour, sublimation). Cramer's (2006) developmental theory of defense mechanisms suggested defense mechanisms follow a developmental sequence such that in early childhood 'immature' (non 'adaptive') defenses such as denial will be predominantly used and, over the course of development, more adaptive defenses will be utilised.

Implicit in this theoretical perspective are a number of important assumptions. Firstly, the role of the unconscious is central. Defense mechanisms are understood to be initiated unconsciously in response to distress. This will have important implications for how researchers investigate the 'coping' or 'defense' processes involved with how individuals attempt to adapt to adversity. It presupposes that researchers have a unique and 'expert' role in 'identifying' what processes individuals are engaging in that the individuals themselves are not aware of (Aldwin, 2007).

The role of the unconscious or pre-awareness have been implicated in a number of other coping models (for example Janoff-Bulman & Yopyk, 2004; Neimeyer, 2001). However, the psychoanalytic perspective's sole focus on unconscious processes is suggested to provide a limited model of coping, when, one considers the intervention based empirical research that demonstrates the conscious coping strategies individuals can learn and successfully use (Bolier et al., 2013; Kraag et al., 2006). A second

theoretical assumption is what constitutes 'adaptive' coping, such, that the 'mature' defenses are perceived to be 'effective' coping and 'immature' defenses are 'maladaptive'. A third assumption suggests defense mechanisms are trait like (Kramer, 2010). That is, they are perceived to arise unconsciously to respond to stressors according to an individual's personality structure (Kramer, 2010) or developmental stage (Cramer, 2006) and, importantly, will not vary according to the situational context of a stressor. Together, these two assumptions present a reductionist conceptualisation of what constitutes 'effective coping' and the model may, again, be a limited view of how coping processes operate. A number of models suggest individuals will employ coping strategies according to the demands of the specific context of the stressor and not as a function of 'inbuilt' personality structures (this will be discussed further in a section below). In addition, Lazarus and Folkman (1984) discuss how the 'maladaptive' defences actually may be adaptive in certain contexts and suggest the context of specific stressors should be critically considered. For example, 'denial' may be effective where stressors are objectively or perceived to be relatively uncontrollable or when used in the short term of a chronic ongoing stressor. Indeed, Carrico, Antoni, Pereira, Fletcher, Klimas, Lechner & Schneiderman (2005) empirically established that denial functioned to elevate depressed mood during the initial stages of diagnosis in relation to unchangeable health conditions. Psychoanalytic perspectives of defense mechanisms have offered a number of suggestions relating to the processes involved in attempting to adapt to adversity. Shortcomings of this model have been discussed. An alternative perspective of coping processes has focused on the temporal factors relating to coping. Main tenants from this perspective will be now discussed.

1.8.3 Temporal theories of coping

Proactive coping theory (Schwarzer, 2001) was introduced into the literature to pay particular attention to temporal aspects relating to coping. A critique Schwarzer (2001) identified was the idea that most coping models focused on 'reactive' coping in response to a stressor and the temporal aspects of coping had often been neglected. Schwarzer's (2001) model purports that coping can be considered across a continuum of time in relation to a stressor: reactive, anticipatory, preventative or proactive coping. In contrast to the psychodynamic perspectives, a key assumption of this model is that individuals will consciously engage in cognitive or behavioural coping efforts when dealing with adversities. In relation to what constitutes adaptive coping, proactive

coping is considered to be the most efficacious. Proactive coping involves a number of ideas. First is the notion of perceiving difficult situations as challenges rather than threats. In addition, individuals are not reactive but proactive and initiate a constructive and goal directed path of action of building up resources. These resources can include personal resources such as self-efficacy and social support. Thus in this model, the processes involved in positive adaptation or 'proactive coping' involves one's perceptions of difficult situations as challenges and individual's having and being goal directed in accumulating additional resources. This is suggested to provide a useful framework to understand more specific coping processes involved with adaptation. As will be seen below, some of these ideas have been borrowed from other frameworks which will be critiqued in more detail later during the review. An important aspect of Schwarzer's (2001) model is that individuals' coping processes should be considered in relation to whether they are engaging in reactive, anticipatory, preventative or proactive coping.

Another theory, that highlights a more specific role of time as a key coping process involved in adaptation to stressors and adversities is the construct of hedonic adaptation. This refers to a cognitive coping process where people become accustomed to a negative stimulus (Frederick & Loewenstein, 1999). In essence this model predicts that the negative emotional effects of a stressor will become tempered over time. Importantly, for 'adaptation' to occur it is suggested that the stressor must be continued and recurring. Thus according to this model, time and ongoing exposure is the key coping process that will influence positive adaptation to the experience of a stressor. Additional insight has been offered by Lyubomirsky (2011) who extends the model of hedonic adaptation. Lyubomirsky (2011) proposes the variability of the stressor, an individual's level of attention to the stressor and their level of aspiration are key processes involved in adaptation over time to chronic or ongoing stressors. Specifically, Lyubomirsky (2011) hypothesises the less variable the 'negative event' or stressor is, the less attention an individual will pay to the negative event which will lead to faster adaptation. Furthermore, reducing one's level of aspirations regarding the stressor will lead to faster adaptation. This process is similar to cognitive reappraisal processes were individuals change their expectations regarding the stressor such as acceptance (Lyubomirsky, 2011).

The models presented in this section have highlighted a number of different coping processes which have centred on temporal aspects and have begun to illuminate a number of additional coping processes suggested to be involved in adaptation. Some are more related to the situational stressor itself such as the ongoing nature of the stressor (Frederick & Loewenstein, 1999) and the variability of the stressor (Lyubromirsky, 2011). Additional processes are more cognitive such as perceiving stressors as challenges (Schwarzer, 2001), changing one's aspirations relating to the stressor (Lyubromirsky, 2011) and individual's being proactive and goal directed in accumulating additional resources (Schwarzer, 2001). A large volume of coping theories that can be grouped under the umbrella of 'cognitive theories of coping' (Alwdin, 2007) have been purported. The following section discusses these perspectives.

1.8.4 Cognitive theories of coping

As highlighted above a number of theoretical perspectives on coping can be grouped under the overarching category of cognitive theories. It is not possible to discuss all perspectives, the selection presented are based upon those that appear most dominant in the literature.

1.8.4.1 Cognitive-relational-motivational theory of coping

Litt, Tennen and Affleck (2011) propose some of the central underpinning tenants of the cognitive-motivational-relational theory of coping have been the 'springboard' for numerous other perspectives on coping. The cognitive-motivational-relational theory (Lazarus, 1991; Lazarus & Folkman, 1984) conceptualises coping as a transactional process and the person and his or her environment are viewed as being in a dynamic, mutually reciprocal, bidirectional relationship. Central to this perspective is the notion of subjective 'appraisal'. The individual is considered to continually appraise demands of a situation or stressor in relation to 1) the significance for well-being, (whether one's goals are thwarted or one's values are threatened), and 2) their perceived personal resources to deal with a situation. When individuals perceive their goals, beliefs or values are threatened and the resources are exceeded, behavioural and cognitive coping efforts will be initiated.

Two overarching coping dimensions are proposed to function to reduce appraisals of distress: problem focused coping and emotion focused coping. Problem focused coping functions to reduce appraisals of distress by attempts at directly dealing with the perceived stressor. Emotion focused coping functions to reduce appraisals of distress by attempting to manage the negative emotions associated with the stressor (Lazarus & Folkman 1984). Emotion focused coping is closely aligned with the construct of emotional regulation (Compas, Jaser, Dunbar, Watson, Bettis, Gruhan & Williams, 2014).

The cognitive-motivational-relational model's conceptualisation of the dynamic nature of this process is important to acknowledge. That is, individuals' coping efforts are perceived to influence one's appraisals of the stressor, and appraisals in turn may influence subsequent coping efforts. This process is considered cyclical in nature and is ongoing until individuals perceive they have sufficient resources to meet their perceived demands of the stressor.

In relation to the effectiveness of coping, an underlying assumption of this model is that there are no inherently overarching 'good' or 'bad' coping processes (e.g. choice of emotion or problem focused coping). This is because the model asserts that individuals' appraisals of the specific stressor are important. For example, theoretically, individuals' perceptions of the controllability of the stressor are important regarding which coping function will be more adaptive. When stressors are perceived to be more controllable, problem focused coping will be more effective, and in stressors that are perceived to be uncontrollable, emotion focused coping will promote better adaptation (Lazarus & Folkman, 1984). Despite this theoretical assertion relating to the 'effectiveness' of coping processes it is reiterated the model suggests people will use both problem and emotion focused coping.

Despite the important theoretical contribution of problem-focused/emotion-focused coping dimensions a number of limitations have been suggested. Hobfoll (2011) suggests that the cognitive-motivational-relational model does not pay enough attention to objective structural constraints imposed on individuals' coping processes. Hobfoll (2011) acknowledges the structural influences on individuals' coping processes using the construct of 'caravan passageways'. These are deemed to be the environmental

factors that can either support and foster or obstruct and impoverish individuals' coping resources. Empirically, the importance of the notion of caravan passageways influencing individuals' coping resources appears to be supported. Hodgetts et al. (2013) identified that parents of children with ASD who displayed severe aggression perceived that professional support services to help them develop strategies to manage their child's aggression were not available. Parents were willing and sought professional support to gain further understanding and skills to manage the aggression (e.g. problem focused coping) but they perceived professional support was unavailable or limited due to insufficient expertise.

1.8.4.2 Meaning focused coping theories

Aldwin (2007) highlights how a number of theories have been introduced into the literature that specify a role for 'meaning-making' in the context of stress (see Park, 2010; Gillies & Neimeyer, 2006; Joseph & Linley, 2006; Park, 2005; Neimeyer, 2001; Park & Folkman, 1997; Janoff-Bulman, 1992; Taylor, 1983). Park (2010) discusses how meaning making coping processes may be particularly adaptive in either objective or subjectively perceived low-control situations which are not readily amenable to 'problem focused' coping. Meaning focused coping involves cognitive strategies that are used to change or reconstruct the meaning of a stressor to reduce distress and increase successful adaptation (Folkman & Moskowitz, 2004). All of the models are underpinned by the notion that reconstructing cognitions are involved with successful adaptation to stressors yet, differences are evident across the models.

Park's (2010) integrated meaning making model suggests that the discrepancy between global and situational meaning is perceived to motivate meaning making coping processes. The degree to which the discrepancy can be reduced via meaning making processes is suggested to promote successful adaptation. Global meaning refers to one's overarching goals, beliefs and values. Situational meaning refers to one's perceptions of the stressor in relation to perceived controllability and relevance to wellbeing. Park (2010) proposes a number of meaning making coping processes that can reduce discrepancies between situational and global meanings. For example, making downward social comparisons with less fortunate others, revising goals and beliefs, identifying benefits involved as a result of the stressor, making reattributions

about the stressor by finding a more 'acceptable' reason for the stressor and accepting the stressor as part of one's circumstances.

Taylor's (1983) cognitive adaptation theory suggests a cognitive coping process involved in successful adaptation to a chronic ongoing stressor, is the degree to which individuals can 'make sense' of the stressor by making causal attributions about the reasons for the event. Taylor (1983) suggests that the cognitive process of developing causal attributions about an event can lead to positive adaptation because it promotes the individual gaining an understanding of the significance of a stressor in their life. A similar process has been described by Janoff-Bulman and Yopyk (2004) who discuss 'meaning-as comprehensibility' where individuals seek to make sense and understand why the adversity is occurring. The purpose of this is suggested to help individuals to gain a 'fit' of the stressor into their existing world views. A more specific process has been articulated in Gilles and Neimeyer's (2004) model, suggesting that individuals begin by starting to ask the questions of "why?", and later "why me?". Benefit finding is another process that has been implicated in a number of models as a cognitive process that promotes reconstructing positive meaning of adversity (Park, 2010; Algoe & Stanton, 2009; Pakenham, 2007; Janoff-Bulman & Yopyk, 2004; Park and Folkman, 1997; Taylor, 1983).

The models all suggest a cognitive processing ability which very young children are not likely to, developmentally, be able to engage in. It is suggested therefore that the generalizability of these models to children need to be carefully considered according to their developmental stage. Indeed, based on comparisons across 58 studies, Skinner and Zimmer-Gembeck (2011) identify that cognitive coping strategies develop during middle childhood (6-9 years). Yet, it is during the onset of formal operations in adolescence that much more sophisticated cognitive coping strategies are likely to be utilised. Indeed, adolescents do appear to engage in meaning focused coping. Guo, Gan and Tong (2013) established that positive reappraisal and acceptance was associated with increase wellbeing and positive affect in the context of an environmental stressor.

A number of differences are evident across the different models of meaning focused coping. For example, Park's (2010) model considers meaning-making as occurring

within an individual's mind. Yet, based on a symbolic interactionism and social constructionist perspective, Neimeyer (2001) identifies interpersonal aspects of meaning-making. In Neimeyer's (2001) meaning making model, emphasis is given to the process of reconstruction through negotiation with others. Furthermore, he highlights that negotiating meaning reconstruction with others will be shaped by personal, familial and cultural factors. In addition, different models posit different propositions relating to the role of the conscious and unconscious in meaning focused coping processes.

Horowitz (1992) theorised meaning making to occur below individuals' conscious awareness. Yet, Janoff-Bulman and Yopyk (2004) proposed that meaning focused coping may at first occur unconsciously but become a more volitional coping effort over time. However, Park (2011) suggests that even when individuals deliberately employ meaning making strategies research has not yet been able to establish whether they are aware of the underlying motive of those strategies as discrepancy reduction. It is suggested this has important implications regarding the methodology employed in research when exploring the constructs of meaning focused coping, it could be that researcher's need to interpret whether individuals may be using meaning focused coping if participants are not aware themselves they are utilising these processes.

1.8.4.3 Perceived control and coping

Folkman (2011) highlights how perceived control is one of the most powerful personal coping resources that can be drawn upon when dealing with obstacles, stressors or adversities. Numerous constructs surrounding control have been proposed in the extant literature including self-efficacy (Bandura, 1997), mastery (Dweck, 1999), perceived competence (Harter, 2006) and the need for competence (Deci & Ryan, 1985). Skinner and Zimmer-Gembeck (2011) suggest, although consensus is not complete, the assumption underpinning these constructs is that people have a need to be effective in their interactions with the environment. A number of coping models propose a process involved in attempting to adapt to adversities are coping strategies that attempt to develop control.

Weisz, McCabe and Dennig (1994) present a multidimensional model of control and coping which draws on the two-process theory of perceived control (Rothbaum, Weisz &

Snyder, 1982). Two coping processes are suggested to function to reduce appraisals of distress by developing a sense of control: primary and secondary control coping. Primary control coping involves influencing one's environment to 'fit' one's wishes. Secondary control coping involves making adjustments to the self or accepting one's circumstances. The central assumption in the model relates to the notion that individuals attempt to reduce appraisal of distress associated with a stressor through attempting to gain a sense of control (Weisz et al., 1994). Similarly, Skinner and Zimmer-Gembeck (2011) purport a major adaptive function of coping strategies is gaining control. In their hierarchical model of adaptive process and families of coping (Skinner & Zimmer-Gembeck, 2011), strategies to develop a sense of control are "through finding actions that are effective in operating contingencies in the environment" (p. 40).

1.8.5 Structural theories of coping

A number of theories focus attention on how culture and various structural factors across individuals' various ecological levels influence and delimit coping options, the experience and appraisal of distress and successful adaptation. Thus, the main contribution of these theories is the hypothesis that individuals are nested within particular ecologies which will influence coping processes and adaptation. This is not to say that these models do not recognise the agency of individuals. Yet, different models pay differential attention to bi-directional influences between individuals and their various systems. Two of these models will be examined to illuminate the main ideas from these perspectives but interested readers may like to refer to the critical discussion paper by Kuo (2011).

Aldwin (2007) postulated a socio-cultural perspective of stress and coping. Coping efforts are hypothesised to bring about change in response to a stressor, which could include individual psychological effects, social, situational and/or cultural effects. The introduction of these widening outcomes beyond the individual is an important contribution of this model by recognising bi-directional influences across various ecological systems. The framework does not postulate what will be 'adaptive' or effective coping, the model postulates the assumption that coping efforts will bring about change in response to stressors. Furthermore, coping efforts can be 'individual' or 'group' such as a family, group of parents, or teachers amongst others. These 'coping

efforts' (whichever efforts may be engaged in) are conceived to be inextricably linked and influenced by the immediate situational and social context which is perceived to be embedded and influenced by the cultural beliefs and resources available. More specifically, cultural resources are perceived to affect situational resources and these are believed to affect the individual's appraisal of the stressor (e.g. if cultural and situational resources provided families with ongoing respite care and access to professional support services to support and help manage the aggression of a child with ASD this would likely positively affect the appraisal of the aggression for siblings). In addition, cultural beliefs and values influence individuals' beliefs and the reactions of others in the immediate situation, which, is also believed to affect individuals' appraisal of the stressor. In this model, how an individual copes is perceived to be affected by four factors: the appraisal of stress, the individual's coping resources, the resources provided by the culture and the reactions of others in the immediate surroundings.

Whilst this model provides a useful heuristic for considering environmental influences, it may be more helpful to integrate propositions of other theories into the socio-cultural perspectives. The construct of emotional contagion (Hatfield, Cacioppo & Rapson, 1993) suggests the emotional reaction of others in the environment communicated through their non-verbal behaviours can be transferred and absorbed by others.

The resource congruence model of coping (Wong, Reker & Peacock, 2006) also implicitly recognises the influences of one's cultural context on the stress and coping process but also pays particular attention to hypotheses relating to 'effective' coping. This model predicates that adaptive coping ensues when there is a 'fit' between one's available coping resources and coping responses in response to a stressor. Additionally, congruence is also believed to be a function of individuals' perceptions that their coping responses are in line with cultural rules and practices (Wong, Reker & Peacock, 2006). That is, what individuals choose to think or do (coping responses) is perceived by them to be an 'appropriate' response in line within their particular cultural beliefs. This model purports that culture affects the coping process by influencing (a) defining what is stressful, (b) predisposing individuals to respond to stress in a customary way, (c) delimiting the nature and the range of resources utilised and, (d) providing cultural knowledge for culturally appropriate coping responses in view of a given stressor.

1.8.6 Conclusion

Review of the theoretical perspectives of coping has highlighted a number of processes purported to be involved in adaptation to adversities. In addition, the perspectives have contributed to gaining an understanding of factors that are considered to influence the coping process. For example, the cognitive motivational theory of coping (Lazarus & Folkman, 1984) introduces the meta-theoretical assumption of the dynamic and the cyclical nature of subjective appraisals relating to the stressor and problem and emotion focused coping efforts. This bi-directional relationship contends that both coping efforts and one's appraisals of a stressor continually influence one another. Hypotheses are also presented and suggest an individual's perceived controllability of a stressor will influence the degree to which coping efforts are more efficacious in reducing those appraisals of distress.

A central theme in a number of models has been the role of making sense of and developing meaning of the adversity in one's life as key processes in adaptation. Janoff-Bulman & Yopyk (2004) identify the process of 'meaning as comprehensibility' where individuals will try to 'fit' the stressor into their existing worldviews. Yet, Taylor (1983) purports how developing causal attributions for the stressor has a role in adaptation by helping individuals to gain and feel a sense of understanding about the stressor and its significance in one's life. The importance of benefit finding has been illuminated by a number of models, where, the significance of this cognitive process is through the individual being able to reconstruct positive meaning of the stressor (Park, 2010; Algoe & Stanton, 2009; Pakenham, 2007; Janoff-Bulman & Yopyk, 2004; Park and Folkman, 1997; Taylor, 1983). Nieymeyer's (2001) model based on the social interactionist perspective, proposes the central role of meaning reconstruction through interaction and negotiation with others. In an extension to the construct of hedonic adaptation, Lyubromirsky (2011) suggests the variability of a stressor will play a central role in the level of attention that one pays to a stressor. It is proposed the less variable a stressor, individuals will attend less to the stressor which is purported will increased the speed at which an individual adapts.

Debate emerging from the literature also centres on the question regarding the role of the unconscious in an individual's coping efforts. An individual's ecological context is given more consideration by a number of other models. For example, Aldwin's (1997)

socio-cultural model highlights the reactions of other's in one's immediate surroundings can influence both individual's appraisals of the stressor and their subsequent coping choices. Wong, Reker & Peacock (2006) has offered additional insight by proposing that 'adaptive' coping responses are those where the individual perceives there is a 'fit' between coping responses which are culturally accepted in one's ecology.

It is suggested these different theoretical perspectives on coping may provide insight into how siblings experience and perceive the effective underpinning coping processes involved with adapting to aggression by a brother or sister with ASD.

1.9 The current study

Hodgetts et al. (2013) identify that a paucity of empirical research has examined how the family, and in particular how siblings, are affected by the aggression by a brother or sister with ASD. Previous research on siblings experiencing aggression by a brother/sister with ASD has highlighted largely negative experiences and emotional, behavioural and psychosocial adjustment difficulties (Pollard et al., 2013; Petalas et al. 2012; Benson & Karloff, 2008; Benderix & Sivberg, 2007). Some of the qualitative research findings provide additional insight into siblings' perceptions of their experiences such as feeling unsafe in their homes and perceiving the aggression as unpredictable. Yet, as a body of research these qualitative studies focused on a descriptive rather than a latent or explanatory level. It is unclear therefore why or how siblings perceive they are particularly affected negatively. It is suggested that further in-depth exploration of siblings' perceptions and how they construct and make meaning of their experience with aggression may provide further insight into the underlying processes that may be contributing to the adjustment difficulties as described above.

To date, research has not comprehensively explored how siblings of children with ASD attempt to adapt to their experiences of aggression. Review of the theoretical coping literature demonstrates a number of different processes suggested to underpin adaptation to stressors and adversities. To the current author's knowledge, only one study to date has investigated the coping strategies siblings employ and believe to be effective in response to aggression by a brother or sister with ASD (Ross & Cuskelly, 2006). However, the quantitative methodology employed in their study is suggested to have prevented an in-depth exploration of why and how siblings perceived these

strategies to be effective. In addition, the questionnaire based methodology precludes siblings articulating other strategies they may employ which were not included in the questionnaire. In light of this, it is argued further research is warranted. Gaining an in-depth understanding of how siblings make sense of their coping processes in attempting to adapt to the aggression, and how they perceive these processes to be effective, will contribute to the evidence base in understanding how siblings, from their own perspective, may be supported with their experiences of aggression.

2.0 The role of the Educational Psychologist

It is suggested the findings of this study will have important implications for the role of the educational psychologist (EP). In England and Wales, EPs work within a legal framework (Special Needs and Disability Act, 2001; Children Act, 2004), which dictates that the needs of children should be considered. When social and/or emotional difficulties are identified in individuals who experience aggression by a sibling with ASD, EPs may undertake assessment of a child's needs and explore possible interventions. The EP is well positioned to direct families and individuals to relevant services should this feel necessary. When siblings are experiencing difficulties as a result of their experience of aggression in the home setting, the EP may wish to work directly with the child or with those who support the child. Examples of EP practice may include therapeutic work, raising awareness of professionals and families, and/or requesting advice and support from other agencies.

3.0 Research aim

The aim of this study is to gain an in-depth understanding of how siblings make sense and construct meaning from their experience of aggression by their brother/sister with ASD. It also aims to develop an in-depth understanding of siblings' experiences and perceptions of their effective coping processes in attempting to adapt to the aggression.

1. What are the thoughts and feelings of adolescent siblings who experience aggression by their brother or sister with ASD?
2. In what ways do adolescents' thoughts and feelings interact in response to their experience of aggression by their brother or sister with ASD?
3. How do adolescents perceive their thoughts and feelings to change over time, if at all, about their experience of aggression by their brother or sister with ASD?

4. What internal or external factors influence adolescents' thoughts and feelings about their experience of aggression by their brother or sister with ASD?
5. What effective coping processes, if any, do adolescents perceive they engage in in response to their experience of aggression by their brother or sister with ASD?
6. In what ways do adolescent siblings perceive their coping processes to be influenced by any internal or external factors?
7. How do adolescent siblings perceive their coping processes to change over time?

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Part two: empirical paper

(word count – 6, 237)

An Interpretative Phenomenological Analysis of adolescent siblings' experiences of aggression by a brother with Autism Spectrum Disorder, and their perceptions of their coping processes

1.0 Abstract

The aim of this qualitative study was to gain an in-depth understanding of how siblings make sense and construct meaning from their experience of aggression by their sibling with ASD, and to explore their perceptions of their coping processes in attempting to adapt to the aggression. Semi-structured interviews with six adolescent siblings were analysed using Interpretative Phenomenological Analysis (IPA). Four superordinate themes were identified and include a threatened and disempowered self, seeking to gain a sense of control, interpersonal coping, and making and changing meaning. Novel findings emerging from the study relate to how the siblings constructed an aspect of their self as devalued through their experiences of aggression. Findings are discussed in relation to the extant literature and psychological theory.

1.1 Introduction

A number of statutory acts, policies and guidelines in the United Kingdom (UK) identify the importance of assessment and intervention of the needs of siblings in response to the challenges associated with a brother or sister with Autism Spectrum Disorder (ASD) (National Institute, 2013; Welsh Assembly Government, 2008). Aggression is not inherent in the diagnosis of ASD; however, epidemiological research has suggested it is highly prevalent in this population with estimates of up to 68% (Hill, Zuckerman, Hagen, Kriz, Duvall, Santen, Nigg, Fair & Fombonne, 2014; Farmer & Aman, 2011). Hodgetts, Nicholas and Zwaigenbaum (2013) identify there is a paucity of empirical research exploring how the family, and in particular, how siblings are affected by the aggression by a brother or sister with ASD.

1.2 Critical review of empirical research: siblings and the experience of aggression by a brother or sister with ASD

Previous research on siblings experiencing aggression by a brother/sister with ASD has highlighted largely negative experiences and outcomes. A small body of quantitative

research has revealed the presence of aggression in children with ASD is associated with increased anxiety (Pollard, McNamara-Barry, Freedman & Kotchick, 2013) and behavioural, peer and emotional adjustment difficulties (Petalas, Hastings, Nash, Hall, Joannidi & Dowey, 2012; Benson & Karlof, 2008; Hastings, 2007). Likewise, a small body of qualitative research also has highlighted negative influences on siblings. Mascha and Boucher (2006) identified the presence of aggression is the stressor of concern most pertinent to siblings surrounding their experience of living with a brother/sister with ASD. Additional insight has been offered by other qualitative studies revealing siblings have described feeling anxious and unsafe in their homes and aggression is perceived to be unpredictable (Petalas, Hastings, Nash, Reilly & Dowey, 2012; Benderix & Sivberg, 2007).

Yet, as a body of research these qualitative studies focused on a descriptive rather than a latent or explanatory level. It is unclear therefore why or how siblings perceive they are particularly affected negatively. It is suggested that further in-depth exploration of siblings' perceptions and how they construct and make meaning of their experience with aggression may provide further insight into the underlying processes that may be contributing to the adjustment difficulties as described above.

The negative outcomes identified in the above empirical research are suggested to pathologise those siblings who experience aggression by a brother/sister with ASD. Yet, a number of theoretical perspectives of coping propose individuals are not passive recipients of adversity but will show agency and make dynamic adjustments to attempt to overcome adversity (Folkman, 2011). Theoretically, coping has been hypothesised as a mediator between adversity and adaptation (Pakenham, 2011; Park, 2011).

In line with the upsurge of the positive psychology movement (Seligman & Csikszentmihalyi, 2000) across the social sciences, it is suggested exploring the construct of coping will provide a shift from a current predominant focus on pathology to understanding the processes involved with how siblings may adapt to their experiences with aggression. Indeed, one study has explored the coping strategies adopted by siblings in response to aggression by a brother/sister with ASD. Ross and Cuskelly (2006) identified the frequency and perceived effectiveness of the coping strategies siblings employed in relation to the aggression. The proportion of siblings who

perceived specific coping strategies to be effective were as follows: emotional regulation (84%), wishful thinking (84%) social withdrawal (89%) distraction (100%), problem solving (93%), social support (92%), resignation (58%), cognitive restructuring (100%), blaming others (60%), and self-criticism (50%). However, the quantitative methodology employed in their study is suggested to have prevented an in-depth exploration of why and how siblings perceived these strategies to be effective. In addition, the questionnaire based methodology employed precludes siblings articulating other strategies they may adopt which were not included in the questionnaire.

1.3 Critical review: theoretical perspectives of coping

The construct of coping is multidimensional and complex; with a plethora of theories from different perspectives (Aldwin, 2011). Review of the literature reveals a number of processes that are purported to be involved with adaptation to adversities. Furthermore, different perspectives suggest a number of factors may influence the coping process.

The cognitive motivational relational theory of coping (Lazarus & Folkman, 1984) emphasises the cyclical nature of subjective appraisals relating to a stressor and problem and emotion focused coping efforts. Hypotheses within this framework suggest that an individual's perceptions of the controllability of a stressor will influence which coping effort will be more effective. Aside from this there are also theories that focus on meaning which emanate from cognitive, social constructionist and symbolic interactionist paradigms. For example, Park (2011) proposed meaning making processes such as acceptance and positive reinterpretation function to reduce discrepancies in global or situational meanings leading to better adjustment. Meaning reconstruction is also a central process in adaptation to stressors for Neimeyer (2001). However, from a symbolic interactionist perspective this process is constructed through interactions with others and shaped by personal, familial and cultural factors. Folkman (2011) hypothesises that meaning-focused coping becomes especially important in stressful situations that are prolonged or chronic, possibly where emotion focused and problem focused coping may not make things better. Lyubromirsky (2011) suggests the variability of a stressor will play a central role in the level of attention that one pays to a stressor. It is suggested that the less variable a stressor, the less attention to that stressor an individual will give. This is proposed to facilitate adaptation. An individuals' ecological context is given more consideration by other models. For example, Hobfoll

(2011) suggests that individuals are positioned within a certain sociocultural ecology. Caravan passageways are proposed to be the environmental conditions that can either support and foster or obstruct and impoverish individuals' coping resources. These are conceived as being largely out of the control by the individual or family, such as access to respite care and professional support services.

With these different perspectives in mind, the question arises of, how do siblings experience and perceive the effective underpinning coping processes involved with adapting to the aggression by a brother or sister with ASD?

1.4 The current study

In response to the above critical discussion of the literature it is suggested that research to date has not explored in depth how siblings experience and cope with aggression by their brother or sister with ASD. This study seeks to address this gap in the literature. It is proposed that exploring how siblings experience, make sense of and construct meaning from their experiences may provide insight into the possible underpinning processes involved with the adjustment difficulties identified in previous research.

Instead of being aligned to a particular theoretical model of coping it is suggested that it is important to gain an understanding of how siblings make sense of their coping processes in attempting to adapt to the aggression, and how they perceive these processes to be effective in order to understand the processes involved in adaptation from their own perspective. It is suggested that this will allow unanticipated findings to emerge, that may not be consistent with propositions from particular theoretical models. It is suggested this research will have important implications for educational psychologists and other professionals supporting families with a child with ASD who demonstrates aggression.

1.5 Research aims and questions

The aim of this study is to gain an in-depth understanding of how siblings make sense and construct meaning from their experience of aggression by their brother with ASD. It also aims to develop an in-depth understanding of siblings' experiences and perceptions of their effective coping processes in attempting to adapt to the aggression. The study will attempt to answer the following research questions:

1. What are the thoughts and feelings of adolescent siblings who experience aggression by their brother or sister with ASD?
2. In what ways do adolescents' thoughts and feelings interact in response to their experience of aggression by their brother or sister with ASD?
3. How do adolescents perceive their thoughts and feelings to change over time, if at all, about their experience of aggression by their brother or sister with ASD?
4. What internal or external factors influence adolescents' thoughts and feelings about their experience of aggression by their brother or sister with ASD?
5. What effective coping processes, if any, do adolescents perceive they engage in in response to their experience of aggression by their brother or sister with ASD?
6. In what ways do adolescent siblings perceive their coping processes to be influenced by any internal or external factors?
7. How do adolescent siblings perceive their coping processes change over time?

2.0

METHOD

This section presents the paradigm and methodology used in this study. Part three: research reflective summary provides a critical reflection of the research methodology. Further detail and justification for the choices made are provided in both Part three and the Appendices.

2.1 Research paradigm: ontology, epistemology and methodology

The study adopted a qualitative research design to develop a rich and in-depth picture of 1) how siblings construct meaning and make sense of their experience of aggression by a brother/sister with ASD and, 2) how siblings make sense of their coping processes in attempting to adapt to the aggression and how they perceive these to be effective.

The research paradigm for this study was based on the interpretivist-constructivist perspective. Consistent with this paradigm a relativist ontology was adopted (the notion that multiple 'realities' exist) and a transactional/subjectivist epistemology ('knowledge' is created and co-constructed between participant and research) underpinned the study (Willig, 2013).

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) was employed as a methodology. It was believed IPA's theoretical underpinnings of

phenomenology, hermeneutics and ideography were particularly suited to providing an in-depth and nuanced understanding of the aims of the study. In line with the theoretical underpinnings of IPA, the researcher aimed to provide insight into participants' unique subjective perceptions in relation to the aims rather than be guided by a predetermined theory (Cohen, Manion & Morrison, 2007). In line with the epistemological position of IPA, it is acknowledged that themes emerging from analysis were interpreted and generated by the unique subjective position of the researcher.

2.2 Participants and inclusion criteria

Six adolescent participants took part in this study. Table 1.1 summarises the participants' demographics. Consistent with recommendations of IPA (Smith et al., 2009), participants were selected purposefully to form a homogenous sample suited to the study's aims. Participants were chosen to reflect the inclusion criteria (Table 1.1). Justification for inclusion criteria is provided in Part three: research reflective summary. Participants are given pseudo names.

Table 1.1: Participants' demographics

Participant sibling	Age of participant sibling	Family characteristics	Participant sibling birth order	Age of proband sibling with aggression and ASD	Gender of proband sibling with aggression and ASD	Geographical Location
Holly	15	Single parent family (female) 3 children	2 nd	12	Brother	South Wales
Stephen	17	2 parent family (male and female) 2 children	1 st	15	Brother	South Wales
George	14	2 parent family (male and female) 3 children	3 rd	18	Brother	South Gloucestershire
Joselyn	14	2 parent family (male and female) 2 children	2 nd	17	Brother	South Wales
Rebekah	17	2 parent family (male and female) 3 children	1 st	16	Brother	South Gloucestershire
Felix	15	2 parent family (male and female) 3 children	3 rd	16	Brother	South Gloucestershire

Table 1.2: Inclusion criteria

- Proband sibling with ASD displayed physical and verbal aggression at least four times per week in the home context.
- Proband sibling had a formal diagnosis of ASD.
- Proband and participating sibling currently resided in the same home.
- Participating sibling aged between 11-19 years.
- Participating sibling had no additional needs (including BAP characteristics, cognitive impairments, psychiatric difficulties).

2.3 Ethical considerations

The Code of Ethics and Conduct (British Psychological Society, 2009) and the Code of Human Research Ethics (British Psychological Society, 2010) was adhered to. Ethical consent was obtained from Cardiff University Ethics Committee. Ethical considerations are described fully in Part three. Head teacher, sibling and parent information letters and consent forms, and sibling debrief forms are detailed in Appendices I to VIII.

2.4 Data collection method

Semi-structured interviews were used to explore siblings' perceptions of their experiences and coping processes. One interview took place with each sibling in their home on a one to one basis. Interviews were audio-recorded and lasted 25-40 minutes. The interview schedule (Appendix VIII) was developed by the researcher using suggestions by Smith et al. (2009). Questions were devised to explore the topic area and were not guided by a predetermined theory. Questions were open-ended to allow siblings to convey perceptions and experiences they deemed pertinent. Dependent on their response, probes were used to elicit a deeper understanding and/or gain clarity.

2.5 Pilot

The researcher considered conducting a pilot interview. The rationale for the pilot was to provide an opportunity to explore the clarity and the utility of the questions in the interview schedule in eliciting the perceptions of the participants. In addition, it was perceived the pilot interview would allow the researcher to practise using the questions and the probes in the schedule. However, a decision was taken not to conduct a pilot. This decision was made due to significant difficulties in recruiting participants.

Increased importance was placed on having a larger number of participants to form the actual sample involved in the study, in order to be able to explore both the convergence and divergence between participants' perceptions. Therefore, the decision was made that all participants recruited for the research were included in the actual study.

2.6 Procedure

The chronological procedure of the study is detailed in Appendix X.

2.7 Analysis of data

Audio-recordings were transcribed verbatim by the researcher. Systematic steps were taken to analyse the transcripts using the framework by Smith et al. (2009). Each transcript was analysed in turn before moving on to the next in keeping with the idiographic focus of IPA. A step-by-step description of the process of analysis is described in Appendix XI and an example of the stages is provided in Appendices XII- XIV. Further information is given in Part three.

2.8 Issues of validity

To increase the validity of the findings the researcher adopted the principles of credibility and transparency suggested by Yardley (2008) and Smith (2008).

To increase the credibility of the analysis the researcher asked an Educational Psychologist to read and review step two and three of the analysis process (see Appendix XI) for one participant (Felix). The Educational Psychologist was given definitions of the different categories of exploratory comments (e.g. descriptive, linguistic and conceptual) and a definition of an emergent theme suggested by Smith et al (2009) (see Appendix XI). The Educational Psychologist was asked to read one participant's transcript and the associated exploratory comments and emergent themes that were generated by the researcher for that participant written directly onto the transcript (see Appendix XII). The Educational Psychologist was asked to comment on her agreement with the exploratory comments and emergent themes generated by the researcher. The researcher and the Educational Psychologist engaged in a discussion regarding the Educational Psychologist's agreement to the researcher's interpretations. The Educational Psychologist perceived the exploratory comments and emergent

themes generated by the researcher were a good reflection of the participant's transcript.

To increase transparency the researcher included the step-by-step description of the process of analysis and examples of the stages (Appendices XI-XV). In addition, in line with suggestions by Smith et al. (2009) verbatim extracts are presented in the findings.

3.0 FINDINGS

The following section describes the findings that emerged from the Interpretative Phenomenological Analysis (IPA). The IPA explored 1) how siblings constructed meaning and make sense of their experience of aggression by their brother with ASD and, 2) how siblings make sense of their coping processes in attempting to adapt to the aggression and how they perceive these to be effective.

Table 2.1 summarises the superordinate and subordinate themes that emerged from the IPA.

Table 2.1: Superordinate and subordinate themes

Superordinate themes	Subordinate themes
A threatened and disempowered self	An aspect of self as devalued Constructing aggression as unpredictable
Seeking to gain a sense of control	Actively searching to predict when Developing strategies to manage the aggression
Interpersonal coping	Relinquishing responsibility Feeling understood A sense of respite
Making and changing meaning	Attributing their brother's aggression to a reduced capacity

	<p>Accepting the way it is</p> <p>Finding the silver lining</p>
--	-------------------------------------------------------------------------------

3.1

Superordinate theme one: a threatened and disempowered self

This superordinate theme illustrates how siblings constructed a negative impact on themselves through their experience of aggression by their brother with ASD. Superordinate theme one is entitled ‘a threatened and disempowered self’. Two subordinate themes emerged from the data: an aspect of self as devalued, and perceptions of a lack of control over aspects of their environment at home.

3.1.1 Subordinate theme one: an aspect of self as devalued

All but one sibling appeared to construct an aspect of self as devalued through their experiences with their brother’s aggression. A range of negative emotions accompanied this perception including feeling “sad”, “low”, “bad”, “upset”, “rejected” and that it was “hard”. As Felix’s reflection encompasses,

Felix:
 “He doesn’t really recognise that I’m trying to help, he recognises me as, as the one who can, he can let out his anger on I guess. It’s (pause) hard (pause) because, like, I’m, I’m there (pause) I’m trying to be the one who’s trying to help.”

Researcher:
 “how does that make you feel?”

Felix:
 “rejected (long pause), by him, and a bit annoyed and sad”

There were differences between siblings regarding how they constructed an aspect of their self as devalued. As Stephen discusses,

“Like (pause) I thought that, like he doesn’t care he hurts me, (pause) like, he didn’t care I’m his brother”

Stephen seemed to perceive his brother didn't care that he hurt him and he didn't care that Stephen was his brother. For Stephen, he appeared to believe that brothers should care and should not hurt each other. It is this discrepancy between how things 'ought' to be and how things 'are' that seemed to create his perception of feeling devalued which elicited negative feelings.

For Holly however, her perception that an aspect of self was devalued was associated with a belief that her brother 'wanted' to hurt her. Holly reflected,

"Well, when I was younger, I used to think, why me? I thought that it was just, he was doing it [the physical aggression] because he *wanted* to hurt me, I used to think (pause)"

For Joselyn, her perception of an aspect of self as devalued appeared to be constructed by a stigma she felt by being the sister of an aggressive brother with ASD. Joselyn describes,

"It affects me [the aggression], it makes *me* feel bad, because (pause) you know, he's my brother and like, he shouldn't be doing that"

What seemed to tie siblings' accounts of constructing an aspect of their self as devalued (e.g. their brothers 'not caring', 'wanting to hurt them' and feeling 'stigma') was a discrepancy between what siblings wanted to/or felt should happen and what was happening.

It appeared that, for some siblings, perceptions of a sense of self as devalued were located in their past. Holly and Stephen's use of past tense and explicitly referring to a previous time period of being 'younger' appeared to highlight the construction of a sense of self as devalued was no longer relevant to them. For Felix and Joselyn, this was different, their use of present tense suggests their perception of their self as devalued and feeling 'rejected' and 'stigmatised' was part of how they currently made meaning of their experience of their brother's aggression.

3.1.2 **Subordinate theme two: constructing aggression as unpredictable**

All siblings constructed their brother's aggression to be variable and unpredictable. For many siblings the unpredictability was a source of tension,

Rebekah:

"you could be in the car, all fine, and then, something will happen, and the.... it will just start [physical aggression] [Rebekah sighed]"

How Rebekah communicated this perception and her sigh at the end of her reflection revealed the tension she felt in relation to the unpredictability of the aggression. Some siblings felt they were in a state of 'vigilance', needing to be 'prepared' and on the 'alert'. As Felix's reflection encapsulates,

"you just don't know exactly when he's going to be aggressive because it can come on at any time. You're just on alert, you feel like, I feel, I dunno like you just have to be prepared, but you can't be. I mean there are times when it is quieter but I'm just always aware that it can happen. It's hard, you know, living like that".

Likewise, Stephen described that he was aware how the aggression could start "suddenly" and this was something that made him feel "anxious". Yet for George, time seemed to play a role in how he had become used to the unpredictability.

George:

"I've just grown, kind of grown to live with the fact that his temper can just change pretty much instantly and he can be aggressive".

3.2 **Superordinate theme two: gaining a sense of control**

The data suggested that all siblings engaged in a process of actively gaining knowledge as means of coping to gain a sense of control over the aggression in their environments. Two subordinate themes emerged from the data: actively searching to predict when, and developing personal resources to directly manage the aggression.

3.2.1 Subordinate theme one: actively searching to predict when

All siblings sought to actively gain knowledge about when their brothers were likely to engage in aggressive behaviour. It appeared that siblings actively engaged in a process of attempting to gain a sense of control over their unpredictable aggressive environments. Siblings appeared to perceive they derived benefit from 'predicting' and 'becoming aware' and 'prepared' for their brother's aggression.

Stephen described how "if it's more predictable you at least start to know the times when it's more likely". Holly reflected how she has come to understand the triggers for her brother's aggression were noises including "fire alarms" and "just cooker alarms". She believed that understanding triggers for the aggression was beneficial for her stating that "as I started to notice more about what seems to make it [the aggression] happen more, it helped me to feel like I know the times when it's more likely and, like.... It's not so random".

Of significance across all of the siblings' accounts was the finding that siblings were actively engaged in the process of observing their brother's behaviours, verbalisations and facial expressions, and the potential environmental triggers to allow them to predict and gain a sense of control over when the aggression was more likely. As George reflects,

"You look, you learn, like, 'can I read my book', 'can I listen to Billy Bragg' and 'can I do my picture' because he says it over and over again, it's a clear sign of him getting agitated. I think we're more used to looking for the signs now and to know (pause) know when it [the aggression] is more likely to come and that's good."

Felix reflected,

"I can look at him and from his, the way he is standing the way he is looking at something you can. If you just see that same expression or body stance long enough each time before he gets angry you kind of clock that well he could kick off, it makes it feel like you can tell when it's going to happen, or well, when it could happen more. I mean there are plenty of times when it [the aggression] will just pop up but at least you can tell a bit when it's going to happen".

3.2.2 Subordinate theme two: developing strategies to manage the aggression

Emerging from the data was the finding that all but one of the siblings engaged in active attempts at developing strategies to manage their brother's aggression. By developing strategies themselves it appeared that siblings gained a sense of personal control over the aggression. For Joselyn, her strategies appeared to instil personal agency and perceived control by allowing her to make different choices and change her behaviour when she thought it to be necessary. As Joselyn's quote epitomises,

"When he starts to make certain noises I back off a bit, calm it down, stop what I'm (pause) be guided by him. You start to recognise over time what helps and what doesn't. You can't do it all the time, sometimes things don't work. But it helps knowing that you can at least try to deal with it [the potential for aggression], like you can actually do something about it."

Holly reflected how through developing an ability to 'calm' her brother down she felt more empowered. She developed a sense of personal control through feeling more able to manage her brother's aggression.

Holly,
"I suppose you learn, before I used to get upset but I know, I've learnt what to do to calm him down. It is still hard him being aggressive, of course it is, but it just doesn't seem as much as a big deal as it used to. It makes me feel better because if we are on our own or in a shop or something, I feel like I can do something about it, I kind of know what helps to calm him down, I feel like I can deal with it."

The process of gaining strategies to deal with the aggression differed across participants. Rebekah reflected the importance of her parents modelling strategies "Like I've watched my mum in the past. Like what she says to him, her tone, the words she says, the things she gets him". As Joselyn's quote above demonstrates, she engaged in a process of developing strategies to manage the aggression through her own trial and error learning.

The significance of developing a sense of control by having strategies to manage their brother's aggression was also epitomised by Stephen's reflection,

“I just sometimes feels like you don’t know what to do, I want to know more [how to manage and deal with the aggression], it feels like I just don’t know how to manage it, what’s best, what’s not (pause), what works or not. It’s like I don’t have the ways to stop it”

3.3

Superordinate theme three: interpersonal coping

Emerging from siblings’ accounts was how they constructed interpersonal coping as an important coping resource. Three subordinate themes emerged from the data. However, there were differences in how siblings perceived interpersonal support as coping and the benefits they derived from social support. These subordinate themes were: relinquishing responsibility, understanding and empathy, and positive distraction.

3.3.1 Subordinate theme one: relinquishing responsibility

The siblings’ accounts all highlighted social support as an environmental coping resource. Importantly, siblings constructed the importance of this resource to ‘relinquish responsibility’ when they appraised the aggression displayed by their brother was too much for them to manage by themselves. As George’s reflection epitomises,

“I wouldn’t ever want to be on my own too long. That’s so sad when you think about it actually.... But it is, it’s so important to me that either mum or dad is about so if [his brother with ASD] is really beginning to get out of control, then... well if they weren’t there to handle things at times I don’t know what I would do”

Although siblings described different levels of active roles in the management of their brother’s aggression, all siblings described occasions where they believed the severity of the aggression exceeded their personal resources. Rebekah described times where she feels “unable to deal with it [the aggression]”. Joselyn discussed how “it sometimes gets way beyond anything I can manage and then I want my mum around so she can deal with it”. For most siblings parents were the primary social coping resource but for Holly her elder brother was also a key resource.

Holly:

“But when it [the aggression] just gets too much, I leave it to my mam or my brother.”

Researcher:

Is that important to you?

Holly

“Yes because if I was on my own and he’s kicking and screaming and that, I could deal with it to a certain extent but then after a while I can’t”

3.3.2 Subordinate theme two: feeling understood

Four siblings described how they derived benefit from feeling understood by others and that others were able to empathise with how they felt in relation to their experience with aggression. As Rebekah considers,

Rebekah:

“It helps knowing that we’re [her family] all in it together”

Researcher:

In what way do you mean?

Rebekah:

“that you feel like people understand how you feel and what it’s like to live like, to know what it’s like to deal with aggression a lot of the time.”

For Holly, she perceived having empathy and understanding by others outside of the family functioned as an important coping resource,

“my friends understand what I am going through, one of my friend’s brother has autism so we talk about it ourselves to each other, she understands what we are going through and that feels good.”

Felix’s account of the ‘most difficult’ part of experiencing aggression by his brother with ASD also highlighted the importance of the social coping resource of feeling understood.

“I guess for me the worst thing is that no matter how many like people come up to you and say I feel bad for you, but they just won’t really understand sort of what has happened, what it’s really like.”

3.3.3 Subordinate theme three: a sense of respite

Siblings' accounts revealed an important social coping resource was spending time with friends which appeared to function as respite from exposure to aggression by their brother with ASD.

Emerging from George's perceptions was the notion that 'spending time with my friends feels like a breather'. Rebekah explained how having time with friends provided a 'sanctuary' where she was able to 'recharge a bit'. Felix described that being with his friends distracted him by being able to 'forget about it' and instead have 'fun with my friends', as he reflects,

"I will try and see my friends on a day that my brother's being really aggressive, that way I can forget about it, and then in turn when I come back later he'll be fine and it was like he was never being bad at all, like he was never being aggressive? that does help because then I spend my time having fun with my friends instead of getting stressed and getting annoyed at my brother."

Having opportunities to remove themselves from the situation by spending time with friends appeared to function as an important social coping resource for siblings.

3.4

Superordinate theme four: making and changing meaning

Siblings appeared to engage in a process of searching for meaning and/or making new meanings about their brother's aggression which appeared to be a process that happened over time. These 'meanings' appeared to profoundly change siblings' appraisals of distress and their feelings surrounding the aggression by their brother with ASD. Three subordinate themes appeared to describe siblings' accounts: attributing the aggression to their brother's reduced capacity, accepting the way it is and finding the silver lining.

3.4.1 Subordinate theme one: attributing aggression to their brother's reduced capacity

Siblings accounts suggested that *over time* all siblings apart from Stephen attributed the reason for their brother's aggression was because of his reduced ability to manage anger and/or because of his autism. Rebekah described how 'I think his autism makes

him see things very differently and he just can't control his aggression'. George reflected that 'he just can't control it at times like he hasn't learnt to do that'.

Importantly, this 'knowledge' or 'belief' appeared to change the siblings' appraisals of distress and feelings towards their brother aggression to something more positive. As Holly reflects,

Holly:

"I used to get upset about why is he doing that to me? But as I got older I realised that it's because he's got autism. Because he's got autism he can't control his anger and if he doesn't like something and he gets frustrated he can't stop himself unless we calm him down."

Researcher:

"How has realising that been for you?"

Holly:

"It's been good because it's made me feel better, you know thinking that his aggression isn't me, it's him, because, he can't help it"

Similarly as Joselyn's quote epitomises,

Joselyn:

"He's got a disability and he can't control it [the aggression] and I think, that, when I, I, started to understand that, that was good for me"

Researcher:

"Why was that good for you?"

Joselyn:

"It just made it [the aggression] seem more understandable"

Siblings' accounts suggested developing attributions that their brother's aggression was because of his lack of capacity or his autism appeared to be a process that happened

over time. For example this was highlighted by Holly who revealed that “as I *got older I realised*”. Felix described how “Ummm, no. I.... I haven’t known it all the time.”

Some siblings talked about how they actively engaged in trying to understand the reasons for their brother’s aggression. Joselyn stated that “I remember asking my mum why? Why is [her brother with ASD] aggressive?’ George reflected how he remembers his parents “sitting him down” to explain his brother’s behaviour.

Siblings’ developing attributions that the aggression was their brother’s lack of capacity changed their appraisals of the aggression to something more positive. They appeared to make sense of the aggression in a different way by making it seem more ‘understandable’. As Felix reflects,

“It makes his behaviour seem more understandable. Once I sort of understood that his behaviour [the aggression] wasn’t because he wanted to hurt me it was because of his not, his brain, his, because of his autism not letting him understand things as easily as I would be able to understand it. I sort of began to realise that it isn’t, he isn’t hurting me because of fun, he’s doing it because I am just there at the time and he can’t control it”.

The importance of this ‘knowledge’, ‘belief’ or attribution is highlighted further by Stephen who was the only sibling who had *not* constructed a belief that his brother’s aggression was due his lack of capacity to control his aggressive behaviour.

“It seems, it just seems strange. Here [at home] he doesn’t care at all (pause). He can control himself in school, in front of teachers. But in the house, he doesn’t have a care in the world, it seems. So why should he do it here? It’s like he doesn’t care”

3.4.2 Subordinate theme two: accepting the way it is

Arising from siblings’ accounts was the finding that when siblings ‘accepted’ their brother’s aggression as part of their circumstances it appeared to positively change siblings’ appraisals and their feelings about living with their brother’s aggression. ‘Acceptance’ refers to a construct where siblings expressed little or no desire for their brother’s aggression to change and they accepted the aggression as part of their circumstances. Siblings appeared to be on a ‘continuum’ of acceptance from having

completely accepted the aggression as part of their circumstance to expressing a clear desire for change. Only Holly and Felix appeared to have completely accepted the aggression as part of their circumstances. Importantly, 'accepting' the aggression and not willing it to change appeared to change siblings' appraisals to something more positive.

Holly's 'acceptance' appeared to change her previous appraisal of the aggression making her feel 'sad' to something more neutral.

Holly:

"It's [the aggression] just how it is. You know, it's there, part of what happens, and you just have to deal with that..... Before it was, well, I did feel sad, but now, it's just the way it is"

Holly's recognition that previously she felt sad appeared to change through her creating a new meaning by accepting the aggression as just 'how it is'.

Developing 'acceptance' appeared to be a process that happened over time. For example this is highlighted when Holly made a comparison to a previous time where she '*did* feel sad'. Felix's reflection talked more about the process of acceptance seemingly relating the acceptance to a belief that the aggression wasn't going to change.

Felix:

Over time, the long term things I've come to realise it's [the aggression] one thing that you know that you probably can't change from him. And so you just have to live with it. You have to um first understand it, then you have to, um realise when it's happening and then um deal with it.

Researcher:

What do you mean deal with it?

Felix:

Like you can't completely change it [the aggression] and so you just have to get used to it. Like why keep wanting to change something you can't completely change?

It appeared that Felix had come to a 'resolution' by accepting the aggression. Felix appeared to believe he should 'stop' wanting to change things because it wasn't going to change. It appeared that acceptance functioned as a means to reduce a discrepancy between a goal that was not achievable.

The notion that the aggression wasn't going to change was also highlighted by Joselyn, but she appeared to be at a different stage on a continuum of acceptance.

Joselyn:

"I wish it would be different.....I've learnt it's [the aggression] his condition [autism] and we have to live with it, we can help him with it, but it's something we have to live with."

Joselyn wished things would be different, which appeared to leave a discrepancy between what she wanted to happen and what was happening. However, it appeared she felt she 'ought' to accept the aggression because she believed her brother was not able to control his aggression.

Yet for one sibling in particular he clearly expressed a desire for change seemingly not having 'simply accepted' the aggression as part of his circumstances. As Stephen reflects,

"It gets me so frustrated. I (pause) I just want it [the aggression] to stop."

3.4.3 Subordinate theme three: finding the silver lining

Emerging from three siblings' accounts was how they constructed a sense of positive personal growth from their experiences with their brother's aggression. These beliefs appeared to change the meaning siblings attached to the aggression to the extent that they perceived benefits from having experienced aggression. The siblings described different types of personal growth. Felix described many personal attributes he perceived he had gained.

Felix:

Um, sometimes I think about how it has made me a better person because ...I know how to, I know how to be patient I know how to wait, I can listen. I can, it's kind of improved me as person, as sort of a social person because instead of being a bossy

person I'm more of a laid back person. I don't really like, sort of, being too loud sometimes. And so I guess I get that from [his brother with ASD], from like his [brother with ASD's] behaviour, because I can sort of think about what I do, what happens at home, and I can put that into real life.

Holly made social comparisons and perceived how she is 'more capable' with dealing with adversity than other people her age.

Holly:

"I think it's made me feel stronger, not in like all senses, but when you, because I've lived with him being aggressive for so long (pause), it just makes me feel like I can handle more than maybe, like other people my age could."

George described how he believed he gained skills around 'empathy'. George believed:

"I think it's made me understanding like (pause), more understanding of how people feel when they're living with something difficult in their life and that's good"

Importantly, siblings' awareness, capacity or willingness to reflect on aspects they felt they gained appeared to enable siblings to re-construct a positive meaning of their experiences with aggression.

4.0 DISCUSSION

The current study aimed to explore the lived experience and coping processes of adolescent siblings experiencing aggression by a brother with ASD. This section begins by discussing key findings, considering these in relation to existing empirical research and psychological theory and highlighting how the findings contribute to and extend the knowledge base.

Emerging from the analysis was the finding that siblings appraised the aggression by a brother with ASD as having a negative impact on their lives and on them as individuals. This is encapsulated in the theme 'a threatened and disempowered self'. The perceived negative impact of aggression on siblings is consistent with previous studies (Petalas et al., 2012; Benderix & Sivberg, 2007; Mascha & Boucher, 2006). Siblings appeared to experience the unpredictability of their brother's aggression as a source of tension and

anxiety where siblings perceived they felt in a state of alert and the need to be prepared. Indeed, Benderix and Sivberg (2007) revealed that siblings experiencing aggression by a brother with ASD also constructed the aggression as unpredictable which, in turn, led siblings to feel unsafe in their homes. The finding that siblings perceived the unpredictability to be problematic and a source of distress could be interpreted through the notion that a sense of predictability within one's environment may be a fundamental need (Golden & Mayseless, 2008). Central tenants of Learned Helplessness Theory (Seligman, 1975), Attachment Theory (Bowlby, 1973) and Hierarchy of Needs (Maslow, 1954) highlight predictability in one's environment as a fundamental need to promote wellbeing, a sense of security, and trust.

A novel theme identified in the current study is that through siblings' experiences of aggression they constructed an aspect of their self as 'devalued'. Siblings' constructions of a sense of self as devalued instigated a range of negative emotions. This finding could be interpreted through symbolic interactionist perspectives of the 'self' (Solomon, 1983). These perspectives advocate the self is a social construct evolving through interactions with others. What appeared to underpin these siblings' 'sense of self as devalued' and the subsequent negative emotions, appeared to be a discrepancy between beliefs siblings held. For example, through Stephen's interactions with the aggression, he constructed his brother 'didn't care' about him, yet, he appeared to simultaneously hold a belief that he wanted his brother to care. The notion that discrepant or contradictory beliefs create distress echoes hypotheses of cognitive dissonance theory (Festinger, 1957). It is suggested this contributes to the knowledge base by illuminating a process underpinning these siblings' negative emotions in response to the aggression.

What is unclear from the current study's findings is the degree to which siblings' 'sense of self as devalued' pervaded their self-concept more globally. Indeed, the multiple self-aspects framework (McConnell, 2011) proposes a global self-concept as a collection of multiple, context dependent selves. It could be these siblings' 'other selves', such as self-beliefs relating to their academic ability or positive personal attributes, may buffer their global self-concept even when an aspect of their self has been constructed as devalued through their experience of aggression by a brother with ASD. It is however tentatively proposed that should siblings consistently construct an aspect of their self as

devalued, this may be a possible underpinning process that could contribute to emotional or behavioural adjustment difficulties.

Positively, these siblings were not passive recipients of their negative experiences surrounding their brother's aggression. Siblings showed agency and made dynamic adjustments. Furthermore, resources in their ecologies, particularly the family, were perceived by siblings as key coping resources to respond positively to perceived challenges.

A key coping resource perceived by the siblings was relinquishing control to others in their environment when they appraised the severity of the aggression by their brother as beyond their own personal resources. Having others in their environment to manage the aggression in these instances was a key source of relief. This finding is consistent with the more dynamic conceptualisations of coping proposed by Lazarus and Folkman (1984) viewing the process of coping as a transaction between the individual and his or her environment. Within this framework, individual's perceived available resources in environments can reduce appraisals of distress surrounding the stressor. Social support was constructed by siblings as a form of coping through the process of feeling understood. This finding could be interpreted using self-verification theory, which asserts that people want to be understood by others and prefer to interact with those who confirm their self views (see Swann, Rentfrow & Guinn, 2003). Empirically, there also seems to be support for this. Lun, Kesebir and Oishi (2008) revealed individuals who perceived increased understanding by others experience greater well-being. Not only do these findings show that social support was perceived by siblings to be a coping strategy (Ross and Cuskelly, 2006), the current study's findings add further insight into how siblings perceived social support to enable them to manage the aggression. These findings highlight the importance of parental capacity and availability to directly manage the aggression when siblings feel overwhelmed.

Siblings described their active attempts to gain a sense of control over the aggression by their brother with ASD. Increasing their sense of control appeared to be a method by which siblings attempted to reduce their appraisals of distress in relation to the aggression. Two key coping efforts emerged where siblings attempted to 1) gain an understanding of when the aggression was more likely and, 2) develop strategies to be

able to 'calm' down their brother. The adaptive function of gaining a sense of control echoes Weisz, McCabe and Dennig's (1994) model of coping who propose the function of adaptive coping efforts are aimed at augmenting control over the environment or the self. A possible implication of these findings relates to the capacity, knowledge and availability in families and professional services to support siblings with gaining a sense of control by promoting the development of strategies to manage aggression. A related and important question to consider is how much responsibility should be placed on siblings to directly manage the aggression? However, as highlighted by these siblings, living with a brother with aggression and ASD is invariably going to place them in a situation where this will be required.

A key coping process emerging from siblings' accounts related to developing attributions for the reasons for their brother's aggressive behaviour. Importantly for siblings, they perceived that developing beliefs their brother's aggression was because of his reduced capacity to manage his anger or because of his ASD made the aggression seem more 'understandable' and helped them to perceive the aggression wasn't 'because of them'. They perceived this had a positive influence on their appraisals of the aggression to which they were exposed. It appeared that this process changed the meaning of the aggression for siblings. Indeed, this process seems to echo meaning focused coping processes documented in the coping literature. Taylor (1983) suggests that the cognitive process of developing causal attributions about an event can lead to positive adaptation because it promotes the individual gaining an understanding of the significance of a stressor in their life.

Emerging from siblings' accounts was the finding that siblings appeared to be on a continuum of acceptance. Some clearly expressed a desire for the aggression to stop whilst others had appeared to have 'accepted' the aggression by their brother as simply being part of their circumstances. Importantly, those siblings who accepted the aggression appeared to positively change their appraisals and feelings about living with their brother's aggression. For example, Holly perceived how accepting the aggression changed her previous feelings of sadness to feeling more neutral, and perceiving it as 'just the way it is'. Indeed, Park (2010) identifies acceptance as a coping process that changes appraisals of distress by changing the meaning that individuals ascribe to a stressor. Importantly, it was unclear the degree to which siblings actively, purposefully

and consciously engaged in 'accepting' the aggression as a means to cope. It is suggested that understanding the underpinning mechanisms involved with siblings developing acceptance is something that deserves further research.

The final key finding that will be discussed relates to the emergent theme of 'finding the silver lining'. Three siblings constructed how they had developed personal growth from experiencing aggression by their brother with ASD. This finding appears to parallel an aspect of Taylor's (1983) cognitive adaptation theory. The construct of self-enhancement refers to a cognitive process proposed to lead to successful adaptation by re-evaluating adverse circumstances positively, thereby mitigating the negative implications of a stressor and protecting self-worth. Importantly, those siblings who were able to reflect on their personal growth appeared to have reconstructed a positive meaning of their experiences with the aggression.

5.0 Strengths, limitations and future research

A strength of this study is suggested to be the use of in-depth interviews and the IPA methodology employed to explore the study's aims. The interviews provided rich and revealing information about siblings' perceptions and the use of prompts helped siblings to articulate their thoughts further. However, there were differences across siblings in their ability to reflect on their experiences and coping processes. It may be useful in future research to incorporate additional participatory methods such as photo elicitation and/or drawings that siblings could engage in pre interviews to be used as a visual device to aid siblings' reflections during in-depth interviews.

The homogenous sample included in this study is considered a strength. Siblings all experienced a relatively high frequency of aggressive behaviour by their brother with ASD (minimum of four times per week). In previous research this methodological factor was not considered.

An important area for future research is suggested to be to further explore the impact of siblings' constructions of an aspect of their self as devalued on their overall global sense of self. It is unclear at present the degree to which their perceptions that an aspect of their self as devalued was pervasive and damaging at a global level.

Some siblings' developed attributions their brother's aggression was due to a lack of capacity to control the aggression and/or due to the ASD. These perceptions appeared to powerfully change siblings appraisals of distress in response to the aggression yet at present it is unclear the mechanisms through which this process occurs.

6.0 Implications for practice and the role of the Educational Psychologist

This study revealed important preliminary findings and a number of recommendations regarding the role of the EP are suggested. However, given the exploratory nature and the small sample size involved in this study, it is suggested it is important additional research is conducted. Three recommendations are suggested that relate to consultation based work where EPs could engage with families where a child with ASD exhibits aggressive behaviour in the home.

Firstly, consultation based work could focus on helping siblings and parents to understand when aggression is likely to be displayed by the child with ASD. For example, this could involve supporting siblings and parents to identify non-verbal and verbal indicators the child with ASD displays and triggers for the aggression. In addition, EPs may support siblings and parents in developing strategies to manage aggression in the family home.

Another recommendation relates to raising awareness to parents of the importance of their availability, or the availability of other adults, to manage the aggression in the home. Based on the findings of the study, the importance of this availability centres on supporting siblings to relinquish the responsibility to others to manage the aggression when siblings feel overwhelmed by the intensity of the aggression.

Finally, EPs could raise awareness to parents about the importance of developing particular attributions within the family about the reasons for the aggressive behaviour by the child with ASD. Specifically, supporting parents to help siblings to perceive the reason for the aggression relates to a reduce capacity in the child with ASD to manage their aggressive behaviour.

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Part three: research reflective summary

Word count: 6682

1.0 Introduction

The current study sought to gain an in-depth understanding of how siblings make sense and construct meaning from their experience of aggression by their brother/sister with ASD, and their experience and perceptions of their effective coping processes in attempting to adapt to the aggression. The following reflective summary will discuss two overarching areas in relation to the current study. The first section focuses on a critical account of the research methodology. A reflection of the philosophical assumptions of the study is offered. The chosen methodology of Interpretative Phenomenological Analysis (IPA) and the method of semi-structured interviews is rationalised, and justifications are given for not adopting the use of other data collection and analysis methods. The inclusion criteria of participants are justified and reflections of the ethical considerations of the research are provided. A critical reflection of the analysis is made, and issues and strategies surrounding validity are discussed. The second section discusses aspects relating to the findings of the study. The section focuses on the study's contribution to knowledge and suggestions for future research are explored. Finally, implications for educational psychology practice are discussed.

1.1 Critical account of the research methodology

1.1.1 Research paradigm: ontology and epistemology

The aim of this study was to gain an understanding of how siblings make sense and construct meaning from their experiences of aggression by a brother/sister with ASD. It also involved gaining insight into their perceptions of how they make meaning of effective coping processes involved with adapting to the aggression. Willig (2013) suggests it is important for researchers to distinguish the ontological, epistemological and methodological orientations of their study (or the research 'paradigm') in order for others to evaluate the 'knowledge' created by the research.

This research adopted an interpretivist/constructivist paradigm because it was perceived to be the paradigm most consistent to explore the research aim. The interpretivist/constructivist paradigm emphasises that 'reality' and 'phenomena' is constructed by individuals and that there are multiple realities which are equally valid

(Chwalisz, Shah & Hand, 2008; Schwandt, 2000). Therefore, the ontological position of the interpretivist/constructivist paradigm, and the ontological position adopted in the current study, was relativism (Denzin & Lincoln, 2005). In line with this ontological position, a transactional subjectivist epistemology underpinned this research, which, suggests that meanings and 'knowledge' in research are co-constructed between the participant and researcher (Denzin & Lincoln, 2005). The general purpose of research within the interpretivist paradigm is focused on understanding the participant's world and how their world, experiences and phenomena are constructed by the participant (Chwalisz et al., 2008).

In contrast, the positivist paradigm subscribes to an ontological position of realism and an epistemology of objectivism (Scotland, 2012). Charmaz (2006) suggests the emphasis positivism places on objectivity, generality, and one unitary truth, serves to reduce the rich complexities of human experiences (Charmaz, 2006, p5). The emphasis on objectivism does not support the focus of the current study. Indeed, Giddens (1991) suggests that experience is thought to be relative to each individual, and specific to their own individual social context. How siblings view and make meaning of their experiences and coping processes in attempting to adjust to the aggression by a brother/sister with ASD may include differences in thoughts, feelings and behaviours. It could also be viewed in terms of a 'process' where experiences and perceptions of coping may become adaptive and could be changeable over time. It is suggested this essence may not be captured through adopting a positivist paradigm. Furthermore, positivism proposes hypothesis testing of pre-existing theory, which can be critiqued on the basis that it prevents unanticipated findings to emerge. Therefore, it is unlikely to allow for new and unexpected insights to emerge in research. Upon reflection of the strengths and limitations of each approach the researcher adopted the interpretivist/constructivist paradigm. This was considered most useful to explore the aims of this study with its focus on the unique subjective perceptions of siblings in relation to 1) how they construct meaning and make sense of their lived experiences, and 2) their perceived effective coping process in attempting to adapt to the aggression by a brother with ASD. A number of methodological approaches were considered and will be discussed and justified in the next section.

1.1.2 Methodology: choosing Interpretative Phenomenological Analysis

Willig (2013) advocates the primary reason for choosing a particular methodological orientation should be the consistency to the research aim. A number of research methodologies were considered to investigate the aim of understanding siblings' lived experience, and the experience and perceptions of effective coping processes involved with attempting to adapt to aggression by a brother/sister with ASD. On reflection of the strengths and weaknesses of different methodologies Interpretative Phenomenological Analysis (IPA) was chosen on the basis it was perceived to be particularly suited to the research aim.

Brocki and Weardon (2006) describe the aim of IPA, "is to explore in detail the processes through which participants make sense of their experiences, by looking at the respondent's account of the processes they have been through." (p.88). Smith (2008) proposes IPA is especially useful when one is concerned with understanding complexity and the processes involved in an individual's experience and how, from their own perspective, they are making sense of an event or phenomena and the meanings they attach to them. It was felt that IPA was particularly suited to the aims of this study to gain an in-depth understanding of how siblings make sense of, and construct meaning from their experiences of aggression by a brother/sister with ASD.

Interpretative Phenomenological Analysis (IPA) is underpinned by the theoretical perspectives of phenomenology, hermeneutics and ideography (Smith, Larkin & Flowers, 2009). IPA's phenomenological approach is concerned with exploring individuals' subjective experiences and perceptions of an experience, process or event but the phenomenological position theoretically prescribes that it does not claim to produce an 'objective truth' about the phenomena being investigated. Its underlying philosophy therefore is there is no objective reality, which is consistent with a relativist ontology. Access to a participant's account is considered partial and complex (Smith et al., 2009).

IPA highlights the researcher's role in interpreting participants' perceptions in a double hermeneutic process where the participant is trying to make sense of their own experiences, and the researcher attempts to interpret participants' interpretations. Smith et al. (2009) suggests the double hermeneutic process enables the researcher to gain

access to participants' perceptions as closely as possible. The 'interpretative' component of IPA was considered essential in facilitating a rich analysis and a holistic understanding to get as closely as possible to siblings' perceptions. The ideographic focus of IPA proposes each participant has a unique subjective experience and calls for the researcher to identify both convergence and divergence within and between participants' perceptions. It was perceived this had a significant advantage for being able to provide a highly nuanced understanding of the aims of this study.

Having rationalised the choice of IPA in relation to the aims of the study a brief explanation will be given as to why other methodologies were not chosen. Discourse Analysis was discounted on the basis that its primary goal is not aligned with the aims of this study. IPA is concerned with cognitions and sense making, however, Discourse Analysis is sceptical regarding the accessibility of cognitions and therefore the primary goal is focused on the role of language in terms of its function in constructing social reality (Starks & Brown Trinidad, 2007). While IPA recognises that cognitions are not transparently available from verbal reports, it is the interpretative analytic process of IPA that aims to make sense and meaning of participants' perceptions of the phenomenon (Smith, Flowers & Osborn, 1997; Smith et al., 2009).

The primary aim of Grounded Theory is to construct a theory about a particular phenomenon that is inductively analysed from the data (Biggerstaff, 2012). Grounded Theory shares some features of phenomenology so could focus on the processes involved in the lived experience (Biggerstaff, 2012) in line with this study's aims. However, the notion that one overarching theory should be generated from analysis using Grounded Theory was perceived to be reductionist for the aims of the study. Indeed, Biggerstaff (2012) suggests there is great complexity and subjectivity involved in the lived experience of a phenomenon. Therefore, people's perceptions, meanings, thoughts and feelings in relation to their lived experience may not be best served by producing one overarching theory as espoused by Grounded Theory. It was felt that given IPA's ideographic theoretical underpinnings and the focus on detailing convergence and divergence in participants' accounts it permitted a more detailed and nuanced understanding of the aims of the study.

It is important to note that it has been suggested that IPA has a number of limitations. For example, Willig (2013) highlights how IPA is dependent on the verbal expressiveness of participants and that individuals may struggle in articulating their thoughts, feelings and perceptions of an experience or phenomena. In response to this suggestion, Smith and Osborn (2008) accept that individuals may find it difficult to express what they are thinking and feeling but suggest the role of the researcher is essential in a process of interpreting what participants say by asking critical questions about what is said and not said. Another limitation is that the role of language may be viewed as problematic for IPA (Willig, 2013). This critique centres on the social constructionist argument that language constructs rather than describes reality. This argument suggests that the transcripts encapsulate more about how participants talk about an experience rather than describing the experience itself (Willig, 2013). However, this notion is challenged by Eatough and Smith (2006) who identify that IPA does acknowledge the role of language in constructing reality, and that experience is never truly accessible, however, IPA proposes that individuals are more than discursive agents and do articulate the essence of their experience and perceptions.

1.1.3 Data collection method: rationale, influence and limitations

This study adopted semi-structured interviews to collect data. This decision was made on the basis that Smith, Flowers and Larkin (2009) propose data collection methods in IPA studies should attempt to collect rich, detailed and first person accounts of individuals' experiences and perceptions of the phenomenon of interest. They propose participants should have the opportunity to speak freely and reflectively, and discuss their perceptions, reflections and experiences most pertinent to them. Smith et al. (2009) argue that in-depth interviews are the best way to access such accounts. However, alternative methods were considered including questionnaires, structured interviews and focus groups.

Questionnaires and structured interviews were rejected on the basis that these methods have been suggested to limit the ability to access rich accounts of participants' perceptions (Willig, 2013). Furthermore, these methods limit the flexibility of the researcher to further explore unanticipated findings emerging from participants' accounts and probe areas that appear to be particularly pertinent to participants. Kitzinger (2005) argues that group processes in a focus group can help participants to

explore and clarify their ideas and views. However, Robson (2002) argues group dynamics may inhibit individuals from speaking freely. This notion contrasts with IPA's idiographic theoretical underpinnings, and for this reason a focus group was rejected.

A semi-structured interview schedule was developed by the researcher (Appendix VIII). It was implicitly recognised the questions in the interview schedule would shape the findings emerging in the study. The schedule of questions was constructed to attempt to allow, as much as possible, the participants to choose to discuss what was deemed pertinent to them in relation to their thoughts, feelings and constructed meanings of their lived experiences. For this reason, the questions in the schedule purposefully aimed to be broad, neutral and not value laden. This measure attempted to place the siblings at the heart of the interview. It was an attempt to limit the researcher's preconceived ideas and knowledge of theoretical coping literature being imposed on the findings.

Smith et al. (2009) recommend the use of probes to support participants in discussing their perceptions further. The researcher used probes to enhance the broad questions in the interview schedule to further explore what participants themselves chose to discuss. Smith et al. (2009) suggests that the order of questions in the schedule can and should be revised if appropriate during the interview to enhance and facilitate rapport building and demonstrate active listening by the researcher. For example, schedule questions were omitted or the order changed if participants had already discussed answers in relation to the questions later in the schedule.

In line with the suggestions by Smith et al. (2009) the researcher aimed to collect rich, detailed and in-depth perceptions of participants. This was facilitated by adaptation of proposals by Gibson (2007) who advocated creating an environment that facilitated communication by developing rapport and a context where participants felt valued and respected. In an attempt to reduce potential power imbalances between the researcher and participant the researcher wore informal clothing and used plain language. In order to reduce potential participant anxiety the researcher explained the structure of the interview and the role of the researcher. Rapport was facilitated by engaging in an informal dialogue by asking age appropriate questions before the interview questions. It was recognised that participants' responses may be subject to social desirability bias (Robson, 2002). To address this, the researcher explained there were no right or wrong

answers and the researcher was interested in their unique perceptions, which, may be different to other siblings who experience aggression by a brother with ASD. For full detail of these steps please see Appendix VIII.

1.1.4 Ethical considerations

The Code of Human Research Ethics (British Psychological Society, 2010) and the Code of Ethics and Conduct (British Psychological Society, 2009) provided the frameworks for ethical considerations in relation to this research study. Ethics approval was sought and gained by a research proposal submitted to Cardiff University's Ethics Committee. Alderson & Morrow (2011) propose ethical considerations should be "woven through every aspect of the research" (p. 5) and this position was adopted by the researcher.

A number of steps were taken to promote the principle of respect for autonomy of persons at various stages across the research process. Respect for autonomy gives potential research participants the freedom to choose and act without being constrained by others, and involves making informed choices about participation in the research (King & Churchill, 2000). Gallagher (2009) proposes informed consent rests on four principles: consent involves an explicit act, for example, verbal or written agreement; consent can only be given if the participants are informed about and have an understanding of the research; consent must be given voluntarily without coercion; and consent must be renegotiable so that children may withdraw at any stage of the research process. These facets were duly considered.

In this study, informed consent was gained using participants' written assent and parental consent before data collection. Verbal consent was collected immediately before starting the interview. Parents and participants were provided with information letters which detailed the true aims of the study, how the data would be used and stored safely, and participants' right to withdraw was made explicit. This was verbally communicated to participants again immediately prior to the interview. Green, Duncan, Barnes and Oberklaid (2003) advocate the use of plain language in information provided to participants to promote 'informed' consent. Careful attention was given to using plain language in participants' information letters in order to promote understanding of the true aims of the study and what was expected of participants.

Participants were verbally debriefed after the interview and were given written debrief letters to explain the purpose of the study, and importantly, to reiterate their right to withdraw at any point up until transcription of the interviews.

The principle of minimising harm means that researchers have an obligation to assess the potential of harm from the research and work arduously to minimise or eliminate them (BPS, 2010). In light of the previous empirical literature detailing largely negative experiences of siblings exposed to aggression by a brother/sister with ASD, it was anticipated the aim of this research had the potential to create distress during the interview. A number of steps were taken to attempt to minimise and manage potential participant distress. The information letters functioned not only to support informed consent but also to reduce distress by attempting to help participants anticipate what would be discussed at interview and thus 'prepare' them. This measure was based upon Seidman's (2013) suggestion relating to distress reduction when participants are discussing sensitive and potentially distressing experiences. Participants also were verbally informed immediately prior to the interview that should they feel upset or feel uncomfortable talking about anything during the interview they could and should stop the interview at any time. Furthermore, if the researcher perceived the participant was becoming distressed and the participant did not request the interview to end the researcher would have stopped the interview. No participants became distressed during the interviews.

1.1.5 Participants and inclusion criteria

The participants were purposefully selected and comprised a small sample of six adolescent siblings (aged 14-17 years) who were currently experiencing aggression by a brother or sister with ASD. More specifically, the inclusion criteria included 1) participants without any additional needs, 2) participants and proband siblings with ASD were required to permanently reside in the family home, and 3) proband siblings with ASD were required to demonstrate physically aggressive behaviour in the family home for a minimum of four times per week. A number of rationales formed the basis of the decisions surrounding the inclusion criteria. Firstly, Smith et al. (2009) advocate IPA requires relatively homogenous purposefully selected samples. Although it is acknowledged the sample size is relatively small it is suggested the small sample size permitted an in-depth and nuanced understanding of the aims of this study in line with

IPA's idiographic theoretical underpinnings. Indeed, as Smith and Osborne (2003) propose, large data sets can result in the loss of "potentially subtle inflections and meanings" (p. 626). Furthermore, a sample size of 4-10 participants has been recommended in a professional doctorate study which uses IPA (Smith et al., 2009).

A strength of the study is proposed to be the homogeneity of the sample. It is perceived that each inclusion criterion contributed to the homogeneity significantly. The inclusion criterion referring to participants not having any additional needs was chosen on the basis that siblings presenting with additional needs may have confounded the study's findings. For example, previous empirical findings regarding the genetic aetiology of ASD suggests siblings are at risk for the Broad Autism Phenotype (BAP) (Gerdtts & Bernier, 2011). Furthermore, the BAP has been linked to siblings' adjustment difficulties (Meyer, Ingersoll & Hambrick, 2011). It is acknowledged, however, the measure of 'not having additional needs' was only assessed via parental report. It may have been useful for the researcher to use a quantitative measure to directly assess for the BAP in siblings. The criterion that proband siblings with ASD were required to demonstrate physical aggression in the family home for a minimum of four times per week is suggested to contribute to the homogeneity of siblings' experiences. In addition, this is considered a strength in that this measure of frequency of aggression exposure has not been previously noted in the literature.

1.1.6 Analysis

Participants' transcripts were analysed using the step by step procedures described by Smith et al. (2009). (See Appendix XI to XIV for the step by step process and examples of each stage of the analysis procedure). IPA considers the researcher's own view of the world and the dynamic process between the researcher and participant, and acknowledges that access to a participant's perceptions during analysis is facilitated by, and also convoluted by, the researcher. Whilst IPA recognises this explicitly within its epistemology, and suggests that the researcher is the 'research instrument' (Smith et al., 2009), the researcher sometimes found the subjectivity involved in the analysis daunting. During the analysis process the researcher was explicitly mindful of her own subjectivity. The researcher remained grounded in the data to reflect participants' perceptions of their experiences. During analysis, the researcher attempted to, as much as possible, 'bracket' her own personal assumptions, beliefs and her knowledge

of the theoretical coping literature to place central importance on and remain grounded in the texts derived from the participants.

Issues of validity in qualitative studies are fervently debated (Hanson, 2008). In IPA, the researcher's role in interpretation and its influence on the research findings is explicitly recognised. Smith et al. (2009) note that the epistemology in IPA recognises there is no one 'true' account. In this light, Smith (2003) suggests that validity in IPA studies is concerned with ensuring credibility of the final account, and is not conceptualised as a single true account. Principles by Yardley (2008) and Smith (2003) were adopted to promote credibility and trustworthiness. These included:

- Step by step procedures by Smith et al. (2009) were used for data analysis to employ a systematic framework for analysis. Throughout the analysis the researcher was reflexive and attempted to bracket as much as possible her preconceived beliefs and values, and her knowledge of the theoretical literature on coping. Central to the entire analysis process was remaining grounded in siblings' accounts.
- Peer review by an educational psychologist to examine the researcher's IPA process for one participant (including the exploratory note taking stage and generation of emergent themes). The peer reviewer largely concurred with the researcher's interpretations. Upon reflection, it may have been useful to engage in this validation strategy with each participant themselves.
- To promote transparency, verbatim extracts were presented in the findings to illustrate how the subordinate themes generated by the IPA have been firmly grounded in the siblings' accounts. The researcher included explanations of the step by step procedures adopted in the analysis and provided examples of these steps in Appendix XI –XV).

1.2 Contribution to knowledge

The current study sought to gain an in-depth understanding of how siblings make sense and construct meaning from their experience of aggression by their brother with ASD. In addition it aimed to develop an in-depth understanding of siblings' experiences and perceptions of their effective coping processes in attempting to adapt to the aggression. As highlighted in the literature review a small body of quantitative research reveals the

experience of aggression by a brother/sister with ASD places siblings at risk for a range of emotional, behavioural and psychosocial adjustment difficulties (Griffith, Hastings & Petalas, 2014; Shivers, Deisenroth & Taylor, 2013). Likewise, a small body of qualitative research revealed aggression as the stressor of concern most pertinent to siblings in relation to their experiences of having a brother/sister with ASD (Mascha & Boucher, 2006). Additionally, siblings appear to construct aggression as unpredictable, which creates feelings of anxiety and feeling unsafe in their homes (Petalas, Hastings, Nash, Hall, Joannidi & Dowey, 2012; Benderix & Sivberg, 2007).

The current research has contributed to the knowledge base by exploring the possible underpinning processes involved in siblings adjustment difficulties by gaining an in-depth understanding of how siblings make sense and construct meaning through their experiences of aggression. In addition, this research sought to challenge the dominant assumption of pathology created by the existing literature by gaining an in-depth understanding of siblings' experiences and perceptions of effective coping processes involved in attempting to adapt to the aggression. Indeed, to the author's knowledge only one study to date examined how siblings cope with the aggression (Ross and Cuskelly, 2006).

The findings in the current study contribute to gaining an understanding of how siblings, from their own perspective experience and make sense of their coping processes. Key findings will be discussed below with a specific focus on how they contribute to the knowledge base.

Unpredictability was a key theme with how siblings made sense of the aggression by their brother with ASD. Siblings appeared to experience the unpredictability of their brother's aggression as a source of tension and anxiety where siblings perceived they felt in a state of alert and the need to be prepared. This finding is suggested to be pertinent because the limited body of literature that has explored siblings' experiences of aggression by a brother/sister with ASD also highlight the perceived unpredictability of the aggression is constructed as distressing (Benderix & Sivberg, 2007). Therefore, an emerging consistent theme across studies is the notion that aggression is constructed by siblings as unpredictable and is perceived as distressing. It is suggested

this finding contributes to the knowledge base by reiterating the significance and potential negative impact of perceptions of unpredictability.

A novel finding emerging from this study is how siblings constructed an aspect of their self as devalued through their experience of aggression. Siblings' constructions of an aspect of their self as devalued underpinned a range of negative emotions. In the discussion section of the empirical paper this finding was interpreted and discussed in relation to symbolic interactionist perspectives of the self (Solomon, 1983) and cognitive dissonance theory (Festinger, 1957). It is suggested this finding contributes to the knowledge base by identifying a novel process that underpinned these siblings' negative emotions in response to aggression. It is tentatively suggested that should siblings consistently construct an aspect of a sense of self as devalued, this may be a possible underpinning process that could contribute to emotional or behavioural adjustment difficulties. In support of this proposition, Linville (1987) suggests that consistency and a lack of flexibility in negative self-perceptions tend to have a 'spill over' effect into other domains. Furthermore, a number of empirical studies establish a correlation between negative self-perceptions and depressive symptoms (AlGhamdi, Manassis & Wilansky-Traynor, 2011; Kim & Cicchetti, 2006; Abela & Taylor, 2003). However, this study was not able to establish the degree to which a sense of self as devalued pervaded siblings self-concept more globally. Indeed, self-concept has been conceptualised as encompassing a multitude of self-beliefs across a range of domains (McConnell, 2011). It could be that positive self-perceptions in other domains have salutatory benefits for siblings' global self-concept.

An interesting finding also related to how some siblings located their perceptions of a self as devalued to their past whilst for others this construction was still a current perception. It is suggested these findings warrant further research which will be discussed in a section below.

The superordinate theme of gaining a sense of control is suggested to be a significant contribution to the literature. This superordinate theme highlighted how siblings engaged in a process of coping that appeared to be underpinned by attempting to gain a sense of control over the aggression in their environments. Siblings described two processes by which they attempted to gain a sense of control over the aggression: 1)

Gaining an understanding of when the aggression was more likely to occur and 2) Developing strategies to manage the aggression. It could be suggested that the finding of Ross and Cuskelly (2006) where siblings demonstrated a coping strategy of 'problem solving' in response to the aggression by a brother/sister with ASD is similar to the processes described by these siblings.

In Lazarus and Folkman's (1984) model of coping 'problem focused coping' can reduce appraisals of distress by trying to directly deal with the stressor itself. However, for these siblings they appeared to make sense of the processes they engaged in as a means to gain a sense of control over the aggression. Indeed, the adaptive function of gaining a sense of control is highlighted in a number of models of coping including Weisz, McCabe and Dennig's (1994) model who propose the function of adaptive coping efforts are aimed at augmenting control over the environment or the self. Furthermore, Skinner and Zimmer-Gembeck (2011) propose perceived control is a powerful coping resource when dealing with stressful life events. The findings in this study are suggested to be important by highlighting specific processes siblings perceived facilitated gaining a sense of control over the aggression in their environments. These were perceived to be effective by siblings in relation to increasing a sense of agency, control and empowerment. It is proposed a key implication relates to how siblings may be supported in developing an increased sense of control. The role that parents may have as well as supporting professional may be central.

Interpersonal coping was a key theme in how siblings' perceived social support supported them in managing the aggression. This finding is consistent with findings by Ross and Cuskelly (2006) who demonstrated siblings used social support as a coping strategy to manage the aggression and perceived this to be effective. However, the current study extends previous findings by revealing underpinning processes with how siblings perceived social support functioned as an effective coping strategy.

All siblings constructed how social support functioned as providing relief and made sense of this as means of relinquishing responsibility to others in their environment to manage their bother's aggression. This was pertinent for siblings when they appraised the severity of the aggression as exceeding what they could manage by themselves. In addition, social support was constructed by siblings as a means to feel 'understood'.

This finding could be interpreted using self-verification theory which asserts that people want to be understood by others and prefer to interact with those who confirm their self-views (see Swann, Rentfrow & Guinn, 2003 for a review). Furthermore, Lun, Kesebir and Oishi (2008) revealed that individuals who perceived increased understanding by others in their social environments experienced greater wellbeing.

Another means by which siblings made sense of social support as a coping resource was as a sense of respite. Siblings described how having opportunities to be with others was a positive experience for them by having a chance to 'have a breather', be able to 'forget' about the aggression and find some 'sanctuary' from their home environments. It is suggested these siblings' perceptions provide a more nuanced understanding of how siblings made sense of social support functioning as an effective coping strategy.

The superordinate theme of 'making and changing meaning' depicted how siblings engaged in a process of reconstructing certain beliefs that appeared to change the meaning the aggression had for them to something more neutral or positive. Theoretically, the processes siblings described appear to be aligned with meaning focused coping processes proposed within the coping literature. Park's (2011) meaning making coping model describes how an individual's appraisals of distress associated with a stressor can be reduced by making changes in either their global or situational appraisals. More specifically, individuals can either change their overarching goals, beliefs or values (global appraisals) or their beliefs about the stressor itself (situational appraisal). These siblings appeared to engage in a process of reconstructing beliefs surrounding the aggression itself.

Consistent with this finding is that Ross and Cuskelly (2006) identified that siblings experiencing aggression by a brother/sister with ASD perceived an effective coping strategy was 'cognitive restructuring'. However, the current study extends these finding by providing a more nuanced understanding of how siblings made sense of reconstructing meaning. Siblings described how they reconstructed beliefs about the reasons for their brother's aggression to perceiving the aggression be related to their brother's reduced capacity. Siblings appeared to make sense of this reconstruction process as adaptive by the aggression then becoming more 'understandable' in their

eyes. The notion that siblings perceived the aggression to be more understandable echoes the coping process advocated by Janoff-Bulman (1992) where adaptation involves of developing comprehensibility for the adversity in one's environment.

The finding of the positive benefits of developing such an attribution could be suggested to be supported by the empirical findings of Hartley, Schaidle, and Burnson (2013). These researchers found that parents perceived greater burden in relation to the behaviour problems (including aggression) of their child with ASD when they believed their child was able to control their behavioural outbursts. In addition, siblings described a process of developing acceptance of the aggression as part of their circumstances. Where siblings had accepted the aggression as part of their circumstances it appeared to change siblings' perceptions of distress surrounding the aggression. Indeed, Park (2010) identifies acceptance as a coping process that can change appraisals of distress surrounding a stressor. Furthermore, Skinner and Zimmer-Gembeck (2011) highlight acceptance can be particularly adaptive when stressors are chronic and ongoing or perceived to be relatively uncontrollable.

It is important to note that siblings appeared to be on a continuum of 'acceptance'. Some siblings clearly expressed a desire for them not to be exposed to the aggression by their brother. The processes involved in developing acceptance are unclear from this study and it is suggested this would be useful to explore in future research.

Lastly, some siblings appeared to re-construct a positive meaning through their experiences with aggression by reflecting on aspects they perceived to have gained. This process could be interpreted using Taylor's (1983) construct of self-enhancement. This refers to a cognitive coping strategy in adapting to adversity by reinterpreting the adversity more positively and protecting self-worth. It was unclear from siblings' accounts whether they engaged in ongoing process of 'reminding' themselves about the perceived benefits they derived. Indeed, Affleck and Tennen (1996) distinguish between 'benefit finding' and 'benefit reminding' as separate coping processes to reconstruct positive meaning. However, what was evident was that those siblings who demonstrated an awareness, capacity or willingness to reflect on aspects they felt they gained appeared to enable siblings to re-construct a positive meaning of their experiences with the aggression.

1.3 Contribution to practice and further questions raised by the study

The study revealed a number of important preliminary findings. In light of these, the following section discusses a selection of possible implications for educational psychology practice. In addition, this section will raise questions and issues in response to the suggested implications for practice. However, given the exploratory nature and the small sample size involved in this study, the suggested implications are tentatively proposed.

It is suggested the main findings of the research could be employed at a strategic level to inform and raise awareness to core services across education, health and social care. EPs could implement raising awareness of how siblings construct and make meaning of the aggression by a brother or sister with ASD and their perceptions of their effective coping processes through training. It is proposed raising initial awareness to various practitioners and professionals across core services is an important aim. Review of the literature revealed the main aims of the study are an under researched area. Therefore, it is possible that professionals across core services may have limited understanding.

EPs could also engage in consultation based work directly with families where a child with ASD exhibits aggressive behaviour in the home. Three specific topics are now explored that consultation based work could focus on.

The superordinate theme of 'gaining a sense of control' illuminated two processes in how siblings described they attempted to cope with the aggression by their brother with ASD. These were actively searching to predict when the aggression was more likely and developing strategies to manage the aggression.

EPs could focus on helping siblings and parents to understand when aggression is likely to be displayed by the child with ASD through consultation based work. For example, this could involve supporting siblings and parents to identify non-verbal and verbal indicators the child with ASD displays and any potential environmental triggers for the aggression. In addition, EPs may support siblings and parents in developing strategies to manage aggression in the family home.

It is suggested these possible implications for practice give rise to a number of considerations. One issue relates to the question of the ethical stance EPs may choose to take surrounding advocating siblings directly manage the aggression by supporting them to develop strategies to deal with the aggression. The ethical question attached to advocating strategies to manage the aggression becomes particularly pertinent when considering article 19 of the United Convention of the Rights of the Child (1989). Article 19 defines that children have a right to 'protection from all forms of violence'. It could be constructed that supporting siblings to develop strategies to manage the aggression may place siblings at even more risk of violence. However, based on the findings of this study and in previous research, siblings of children with ASD who display aggression are indeed placed in a position where they are required to manage aggression. Therefore, based on the findings of this study, it is suggested that empowering siblings with knowledge and strategies to deal with the aggression is important and could offer salutary benefits to siblings who are placed in this challenging position.

An additional issue is suggested in relation EPs supporting siblings and parents to develop strategies to manage the aggression by the child with ASD. This question centres on the knowledge base of EPs and time constraints as potential barriers to change. A number of evidenced based interventions are available focusing on managing aggression in children and adolescents with ASD based on behavioural and cognitive paradigms (Brosnan & Healy, 2011; Singh, Lancioni, Manikam, Winton, Singh, Singh, & Singh, 2011; Matson, 2009; Sofronoff, Attwood, Hinton & Levin, 2007). However, a question posed is, to what degree are EPs aware of this knowledge base? How do EPs feel about their own skills to support families to develop strategies to manage the aggression of the child with ASD? When one considers the findings of Hodgetts, Nicholas & Zwaigenbaum (2013) the notion of the knowledge base of the EP as a potential barrier to change may be pertinent. Hodgetts et. al (2013) identified that parents of children with ASD who display significant aggression perceived that professionals supporting the family with the aggression of their child had insufficient skills to support positive change.

A separate but related issue raises the question of whether EPs perceive they have sufficient time to engage with families for, potentially, multiple consultations? It is suggested it is likely multiple consultations will be needed to raise siblings' and parents' awareness and develop their knowledge of underpinning principles of the various

paradigms of intervention and strategies. EP potential time constraints may be a real barrier to this change process.

Another recommendation for EP practice in consultation based work with families relates to the subordinate theme of 'relinquishing responsibility'. This subordinate theme revealed siblings perceived that being able to relinquish responsibility to others to manage the aggression when they feel overwhelmed by the intensity of the aggression, was an important coping process. An aspect of EP consultation based work could focus on raising awareness to parents of the importance of their availability, or the availability of other adults, to manage the aggression in the home. However, a possible question relating to this suggested implication is whether there is availability in the family to always have an adult present to be able to manage the aggression.

The final suggested implication for consultation based EP practice relates to the subordinate theme of 'attributing their brother's aggression to a reduced capacity'. This subordinate theme illuminated that over time siblings constructed the reason for their brother's aggression to be related to his reduced capacity to manage his aggressive behaviour and/or because of his ASD. Constructing the aggression in this way appeared to be positive for siblings and a process of coping that unfolded over time. EPs could raise awareness to parents about the importance of developing particular attributions for the aggressive behaviour by the child with ASD within the family. Specifically, EPs could support parents to help siblings perceive the reason for the aggression relates to a reduced capacity in the child with ASD to manage their aggressive behaviour. Indeed, as discussed in the literature review, a range of empirical research suggests aggression in individuals with ASD may be related to a reduced capacity due to core deficits of the disorder. For example, evidence from neuro-anatomical studies involving the amygdala suggests that individuals with ASD have problems with the perception and regulation of emotions (Adolphs, Sears, & Piven, 2001; Fine, Lumsden, & Blair, 2001). Furthermore, individuals with ASDs have been found to have a reduced capacity to engage in emotional regulation strategies such as cognitive reappraisal and distraction in comparison to controls (Samson, Huber & Gross, 2012; Konstantareas & Stewart, 2006). However, a question emanating from this suggested implication for EP practice is as follows. Could constructing such a belief system in the family disempower families to the possibility of supporting positive change

in reducing the aggression? Therefore, it is suggested it is important for EPs to be mindful of supporting families to construct a balanced view. Aggression in the child may reflect a current reduced capacity to manage their aggression yet also, positive change is possible.

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Appendices

APPENDIX I:



School/Provision

Dear [Title] [Sir Name]

Re: Perspectives of typical siblings exposed to frequent aggressive behaviours by their autistic sibling: An exploration of moderating variables affecting typical siblings' adjustment

I am a Trainee Educational Psychologist (TEP) on the Doctorate in Educational Psychology professional training programme at Cardiff University. I am interested in conducting some research in your school and as part of my doctoral thesis I intend to explore the adjustment and experiences of siblings of children with autism who display aggressive behaviour. This research intends to inform support services for children and young people in education and community settings.

The following inclusion criteria applies for the research.

- Male/female siblings aged 11-19 years who are typically developing and have no additional needs/difficulties.
- Siblings must have a sibling with a formal diagnosis of autism (and no other additional needs/disabilities) who permanently resides at the family home.
- One parent of both the typically developing sibling and child with autism who permanently resides in the family home.

In order to participate in the research one parent and TD sibling participants will be required to complete two questionnaires: (1)* the Strengths and Difficulties Questionnaire (a measure of the siblings' adjustment) and (2)* the Aggression Questionnaire (measure of aggression in the child with autism from the perspective of the parent and the sibling).

Some siblings (a total of 12 out of the 50 original participants) will then be asked to take part in a short face to face interview with the researcher for a maximum of forty minutes. The questions used within the interview will explore the thought and perceptions of having a sibling with autism who displays frequent aggressive behaviour.

All data and personal information will be held securely and at the point of transcribing the interviews the information will be completely anonymous. All participants can withdraw from the study at any time up until the point of anonymising the data. Ethical approval has been provided by the School of Psychology, Cardiff University. The researcher has a full enhanced CRB check. The research will be supervised by Dr. Simon Griffey (Research director, Doctorate in Educational Psychology Professional Training Programme).

If you feel that you have children/young people in your setting who meet the inclusion criteria and may wish to engage, then I will contact you on (insert date) to discuss the research further. If you

do not wish to engage with the research could you please fill in the opt-out form with stamped addressed envelope provided and sent it back within one month.

After one month subsequent to sending out this letter the researcher will contact those gatekeepers whom the researcher has not had response from. The researcher then will request the gatekeepers to disseminate research packs to families identified as potentially meeting inclusion criteria.

I very much you are happy to part take in the study and look forward to hearing from you soon,

Kind Regards,

Una Hicks
 Researcher and Trainee Educational Psychologist

<p>Una Hicks</p> <p>Trainee Educational Psychologist Cardiff University Tower Building Park Place Cardiff CF10 3AT</p> <p>Tel: 07449790328 Email: hicksue@Cardiff.ac.uk</p>	<p>Dr. Simon Griffey</p> <p>Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT</p> <p>Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk</p>
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<p><i>Dr. Simon Griffey</i></p> <p><i>Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT</i></p>	<p><i>Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk</i></p>

* The SDQ and Aggression Questionnaire were later omitted from the research study to focus solely on the qualitative component of exploring siblings lived experience and their perceptions of their effective coping processes.

Appendix II: Gatekeeper opt-out letters

If you wish to withdraw from this research please complete this form and return it in the stamped addressed envelope provided by [insert date]:

I _____ (name)
of _____ (school name)

wish to be withdrawn from the research:

“Perspectives of typical siblings exposed to frequent aggressive behaviours by their autistic sibling: An exploration of moderating variables affecting typical siblings’ adjustment”.

Appendix III: Gatekeeper consent form



Cardiff University School of Psychology

'Perspectives of typical siblings exposed to frequent aggressive behaviours by their autistic sibling: An exploration of moderating variables affecting typical siblings' adjustment.

The above research is being conducted by Una Hicks, Trainee Educational Psychologist, who is on the doctorate in Educational Psychology Professional Training Programme as part of her doctoral thesis. Please could you read and complete the following statements and sign at the bottom of the page if you agree to take part in the study.

I estimate that approximately _____ families that are known to me are likely to meet inclusion criteria.

I consent to disseminating research packs to families who I believe are likely to meet inclusion criteria.

Signed: _____ Name: _____

School/Voluntary Organisation: _____ Dated: _____

Una Hicks Trainee Educational Psychologist Cardiff University Tower Building Park Place Cardiff CF10 3AT Tel: 07449790328 Email: hicksue@Cardiff.ac.uk	Dr. Simon Griffey Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk
<i>In the case of any complaint please contact:</i> Dr. Simon Griffey Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk	

APPENDIX IV:

Information letter to parent/carers



Dear [Title] [Name]

Re: An Interpretative Phenomenological Analysis of adolescent siblings' experiences of aggression by a brother with Autism Spectrum Disorder, and their perceptions of their coping processes

My name is Una Hicks and I am a Trainee Educational Psychologist (TEP) on the Doctorate in Educational Psychology professional training programme at Cardiff University. I am required to undertake research as part of course requirements. I was hoping you would be happy for your son/daughter to take part in the following research.

What is it about?

I'm interested in finding out about how sibling experience and feel they cope and deal with physical aggression by their sibling with autism. Not much research is out there on supporting siblings and even less about how they experience and cope with the aggression by their brother or sister with autism.

Why take part?

- I'd really like for you to feel your family's time is valued and you gain something by taking part. Once I've carried out the research I will make a short leaflet about the findings from the research for the siblings who participated. The leaflet will tell them about what can help to support brothers and sisters who experience aggression by their sibling with autism.
- It will offer siblings a unique chance to have a 'voice' which is something that has been unrepresented by research.
- It is hoped the findings will contribute to supporting siblings, families and educational and community support services when a sibling experiences aggression by their brother or sister with ASD.

What is involved?

- Your child **without** autism will be asked to take part in a face to face interview with the researcher which will last for approximately 30-40 minutes. The questions involved will attempt to explore their experiences and how they cope with the aggression by their sibling with autism. The interview will be audio-recorded.

Who is able to take part?

The research has certain 'requirements' which include the following:

- Participating male/female siblings must be aged 11-19 years and have no 'additional needs/difficulties' themselves.
- Participating siblings must have a brother or sister with a formal diagnosis of autism (and no other additional needs/disabilities).
- Sibling(s) with autism must display physically aggressive behaviour at least four times per week in the family home.
- Both participating siblings and the sibling with autism need to permanently reside at the family home.
- At least one parent of both the participating sibling(s) and child/young person with autism must permanently reside in the family home.

All data and personal information will be held securely and at the point of transcribing the interviews the information will be completely anonymous. All participants can withdraw from the study at any time up until the point of anonymising the data (approximately two weeks after the interview). Ethical approval has been provided by the School of Psychology, Cardiff University. The researcher has a full enhanced Disclosure and Barring Service (DBS) check. The research will be supervised by Dr. Simon Griffey (Research Director, Doctorate in Educational Psychology Professional Training Programme).

I hope very much you are happy for your child to part take in the study. If you wish for your child to participate could you please fill in the consent form included within this pack and return it in the stamped addressed envelope.

I look forward to hearing from you soon,

Kind Regards,

Una Hicks
Researcher and Trainee Educational Psychologist

<p style="text-align: center;">Una Hicks</p> <p style="text-align: center;">Trainee Educational Psychologist Cardiff University Tower Building Park Place Cardiff CF10 3AT</p>	<p style="text-align: center;">Dr. Simon Griffey</p> <p style="text-align: center;">Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff</p>
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APPENDIX V

Parent consent form



Re: An Interpretative Phenomenological Analysis of adolescent siblings' experiences of aggression by a brother with Autism Spectrum Disorder, and their perceptions of their coping processes

Dear Parent/Carer,

Please could you read and tick the following statements and sign at the bottom of the page if you agree or your child to take part in the study.

One of my children has a formal diagnosis of autism and no 'additional needs' e.g. any other diagnoses.

My child with autism displays physically aggressive behaviour at least four times per week in the family home.

My child with autism and their sibling permanently live in the same family home.

My child who will take part in the study (***not the child with autism***) has no additional needs.

I understand my child taking part in the research will have a face to face interview with Una that will last for approximately 30-40 minutes. This interview will explore my child's experiences and how they deal and cope with the aggression by their sibling with autism.

I understand that the interview will be audio-recorded.

I understand that all data and personal information will be held securely and at the point of transcribing the interviews the information will be completely anonymous.

I understand that my child or I can withdraw my child from the study at any time up until the point of anonymising the data about two weeks after the interview.

Ethical approval has been provided by the School of Psychology, Cardiff University.

Una has a full enhanced Disclosure and Barring Service check.

I understand that I am providing my contact details so Una is able to get in contact with me to make arrangement for the interview. These contact details will NOT be passed on to anyone else.

Parent's name

Parent's telephone number

Parent's email address

Parent's home address

Please tick how you would prefer me to get in contact with you.

Signed: _____

Name: _____

Dated: _____

<p>Una Hicks</p> <p>Trainee Educational Psychologist Cardiff University Tower Building Park Place Cardiff CF10 3AT</p> <p>Tel: 07449790328 Email: hicksue@Cardiff.ac.uk</p>	<p>Dr. Simon Griffey</p> <p>Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT</p> <p>Tel: 02920 870366 Email:</p>
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griffeysj@cardiff.ac.uk	
<i>In the case of any complaint please contact:</i>	
<p>Dr. Simon Griffey</p> <p><i>Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT</i></p>	<p><i>Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk</i></p>

APPENDIX VI Participant's information letter



Hi!

my name is
This is me:

Una

and I am a Trainee Educational Psychologist.



I'm carrying out a research project that I hope you may be prepared to take part in. I was wondering if you would read this short information letter which will explain a bit about it and see if you would like to take part.

What is it about and why should I take part?

I am interested in finding out about what it is like to

experience and what supports young people to deal with physical aggression by their brother or a sister with autism. The study is called:

An Interpretative Phenomenological Analysis of adolescent siblings' experiences of aggression by a brother with Autism Spectrum Disorder, and their perceptions of their coping processes

When I've finished the research I will provide a short leaflet to all of the siblings involved in this research. This will show how siblings experience and cope with the physical aggression by their sibling with autism.

- You choosing to take part may also help other young people experience aggression by their siblings with autism. The findings of this research will be shared with professionals supporting families of children with autism.
- Young people don't always get asked about things that affect them and providing the opportunity for you to share what you think is important. You know best about your experiences and understanding those experiences is best to come from you!

What will happen and what will I have to do?

If you agree to take part you will participate in a face to

face interview. It will last for about 40 minutes. The questions will be about what it is like to experience aggression and what you believe helps you to deal the aggression by your brother or sister with autism.

To help me remember all of the things you say I will record (just the sound!) what you say. I will then type up that information and from that point on all of what you have said will be completely anonymous so no-one will know it's you.

If you decide to take part you can decide to stop at ANY point up until I've typed up and anonymised your interview (about two weeks after the interview).

I'm really interested in everything that you have to say but please don't feel as though you have to take part, because you don't!

Now what?

If you would like to take part you will need to fill in the consent form attached to this letter and your parents will also need to fill in their own consent form. Then please send them back to me using the stamped addressed envelope. If you want to know more about this study please feel free to ask me any questions. You can either ask your parents or carer to get in contact with me using this email address hicksue@cardiff.ac.uk or you can ask me on the day.

Thanks!

for reading this and I hope to hear from you/see you soon!
Una Hicks.

Trainee Educational Psychologist

<p>Una Hicks</p> <p>Trainee Educational Psychologist Cardiff University Tower Building Park Place Cardiff CF10 3AT</p> <p>Tel: 07449790328 Email: hicksue@Cardiff.ac.uk</p>	<p>Dr. Simon Griffey</p> <p>Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT</p> <p>Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk</p>
<p><i>In the case of any complaint please contact:</i></p>	
<p>Dr. Simon Griffey</p> <p>Research Director DEdPsych Professional Training Programme Cardiff University</p>	<p>Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk</p>

Tower Building Park Place Cardiff CF10 3AT	
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APPENDIX VII
Participant consent form



My consent form - agreeing to take part

An Interpretative Phenomenological Analysis of adolescent siblings' experiences of aggression by a brother with Autism Spectrum Disorder, and their perceptions of their coping processes

Could you please read and **tick off** the points below and **sign at the bottom**. Please then send it directly back to me using the stamped addressed envelope.

My sibling with autism is physically aggressive at home at least four times per week.

My sibling with autism and I both permanently live in the same family home.

My sibling with autism and I live with at least one of our parents.

I agree to take part in a face to face interview with Una which will last about forty minutes. The questions within the interview will explore my experiences and what I believe helps me deal with physical aggression by my sibling with autism.

I understand that the interview will be audio-recorded.

I understand that all my data and personal information will be held securely and will be transcribed and anonymised about two weeks after the interview.

I understand that I can stop taking part whenever I want up until my interview has been transcribed and anonymised.

I understand there has been ethical approval for this study by the school of psychology in Cardiff University.

I understand that I am providing my contact details so Una is able to get in contact with me to make arrangement for the interview. These contact details will NOT be passed on to anyone else.

My name

My telephone number

My email address

My home address

Please tick how you would like me to get in contact with you.

Signed: _____

Name: _____

Dated _____

APPENDIX VIII
Participant debrief form



Thank You!!!!

very much for participating in this research project, it is really appreciated because it could not have been carried out without you!!

The purpose was to explore how you think and feel about your experiences and how you believe you cope and deal with the aggression your sibling with autism displays.

It is hoped that this research may help to develop support services to families of children with autism who display aggressive behaviours.

The information you have given will be stored securely and it won't be passed on to anyone else.

The data will be transcribed from the recordings of the interview and then anonymised so no one will be able to trace back what you as an individual said.

Remember, you can withdraw up until two weeks after this interview.

If you need any further information please contact the researcher, Una Hicks. If you have any complaints then please forward information to Dr. Simon Griffey, Research Director in the Doctorate of Educational Psychology Training Programme. You can find his contact details at the bottom of this letter.

Signed: _____

Name: _____

Dated: _____

Una Hicks Trainee Educational Psychologist Cardiff University Tower Building Park Place Cardiff	Dr. Simon Griffey Research Director DEdPsych Professional Training Programme Cardiff University Tower Building
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<p style="text-align: center;">CF10 3AT</p> <p>Tel: 07449790328 Email: hicksue@Cardiff.ac.uk</p>	<p style="text-align: center;">Park Place Cardiff CF10 3AT</p> <p>Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk</p>
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<p style="text-align: center;">Dr. Simon Griffey</p> <p style="text-align: center;"><i>Research Director DEdPsych Professional Training Programme Cardiff University Tower Building Park Place Cardiff CF10 3AT</i></p>	<p><i>Tel: 02920 870366 Email: griffeysj@cardiff.ac.uk</i></p>

APPENDIX VIII

Format, procedure and interview schedule of semi structured interview

The following structure has been adapted from the work of and suggestions by Gibson (2007). Each element aimed to create an environment that facilitated communication and promoted a positive experience for participants in order to promote successful and in-depth exploration of their perceptions (Gibson, 2007).

Part one: Pre-semi structured interview procedures

Rapport building is a critical part of exploring young people's perceptions (Gibson, 2007). Gibson (2007) proposes that one way to facilitate this is to provide verbal and written contact before the starting with the interview. In addition to the ethical importance of the child assent and information letter (Appendix VII), the aim of these forms was to develop rapport by promoting a relationship based on respect and valuing participants' choices in line with the suggestion of Gibson (2007). Creating opportunities where choices are created and participants are able to make decisions are suggested to develop supportive relationships where participants feel they are able to speak out and express their perceptions (Shier, 2001).

Part two: Interview procedure – developing further rapport

A number of steps were taken before engaging in the semi-structured interview to build rapport further and support a context where it was hoped participants would feel more at ease with communicating their perceptions.

- Interviews took place in participants' homes where it was hoped they would feel more at ease. The researcher wore informal clothing. The interview took place in a room of participants and their parents choosing.
- A statement was given to participants that included:
 - The structure of the interview and the role of the researcher with the purpose of reducing any anxiety in response to any uncertainty they may have.
 - The purpose of the interview was briefly summarised again to further establish informed consent.
 - A statement to explain if any point there were questions they felt uncomfortable with or they felt upset at any time they could and should ask for the interview to be stopped and if it was perceived by the researcher they became upset the interview would be stopped.
 - A brief statement detailing there were no right or wrong answers to any of the questions.
 - Participants were asked if they were happy to continue.
- A number of age appropriate informal questions were asked to participants to develop further rapport. These included:
 - What school year are you in?
 - What are your favourite things about school?
 - What is the subject you do best in?
 - If I asked your best friend to describe you, what do you think they would say?

- What are your favourite things to do?

Part three: Interview schedule

Q1 What does the word aggression mean to you?

Q2 Everyone's experiences will be different. I'd really like to find out about how you experience things. What is it like living with [name of sibling with ASD]'s aggression?

Prompts (if needed or appropriate)

How is that for you?

Why do you think that?

How does that make you feel?

Why do you/did you think that?

Have you always felt like that?

Q3 What things do you find hard about living with [name of sibling with ASD]'s aggression?

Prompts (if needed or appropriate)

Why is that?

What makes you feel that way?

Have you always felt like/though that?

Are there things that help you or have helped before with that?

How do you deal with that?

Are there people that help you with that?

Why does that help?

Q4 In what ways do you think your thoughts or feelings have changed about [name of sibling with ASD]'s aggression?

Prompts (if needed or appropriate)

Why did that change?

What do you think sparked off that change?

How did you come to realise that?

In what ways do you think that has helped you?

Q5 Why do you think [name of sibling with ASD] is aggressive?

Prompts (if needed or appropriate in line with response)

Have you always thought that?

In what ways do you think that affects how you feel about the aggression?

Q6 What has been important to help you feel better about [name of sibling with ASD]'s aggression?

Prompts (if needed or appropriate in line with response)

Why is that?

How did that make you feel better?

What did that do to make you feel better?

Q7 Could you tell me about things you do or have done to help you deal with [name of sibling with ASD]'s aggression?

Prompts (if needed or appropriate in line with response)

How does that make you feel better?

Why does that help?

Q8 Could you tell about anything you've learnt or know that helped you feel better about [name of sibling with ASD]'s aggression?

Prompts (if needed or appropriate in line with response)

How does that make you feel better?

Why does that help?

Q9 How do people around you help you feel better about [name of sibling with ASD]'s aggression?

Prompts (if needed or appropriate in line with response)

How does that make you feel better?

Why does that help?

Q10 Could you rate from 1-10 how able you feel to deal with [name of siblings with ASD's] aggression?

What makes it a x and not a x?

How does that make you feel better?

Q11 What advice would you give to someone to help them deal with frequent aggression by their brother or sister with ASD?

Prompts (if needed or appropriate in line with response)

Why do you think that would help?

What do you think would help them feel better about the aggression?

Part four: Closing the interview

Participants were thanked for their time. As part of an informal debriefing process an opportunity was given for participants to ask any questions that may have arisen after the course of the interview. In addition, participants were given formal debrief forms (Appendix VIII). Participants were asked if they wanted to be provided with an information sheet of the study's findings after completion of the research write up.

APPENDIX X

Procedure

Ethical approval was Cardiff University Ethics Committee. Gatekeeper information letters, consent and opt-out forms were sent to Head Teachers of Special Schools for autism in South Wales, South Gloucestershire (see Appendices I-III). It is important to note that the current study was not the original study, which sought to investigate whether aggression by a brother or sister with ASD predicted siblings' adjustment difficulties using quantitative measures. It also sought to explore possible moderating variables of siblings' adjustment using a qualitative methodology to explore siblings' perceptions of their experiences of aggression, and coping efforts. However, there were significant difficulties with recruitment preventing the quantitative aspect of the study from being possible. In hindsight, it seems this was too ambitious given the specific inclusion criteria of the study, and limited time period for conducting the study.

The researcher had limited response from Head Teachers. Subsequently, the researcher made phone contact to recruit. This was more successful. Two Head Teachers agreed to identify possible families and send out research packs. Six families agreed to take part. With such a limited response, it was necessary to withdraw the quantitative component of the study, as this would have implications for the reliability and validity of the study. The research aims were amended to solely focus on gaining an in-depth understanding of how siblings make sense and construct meaning from their experience of aggression by a brother or sister with ASD, and to explore siblings' experiences and their perceptions of their effective coping processes. In light of the change to the study, siblings and parents were sent amended consent and assent forms.

APPENDIX XI

Data Analysis Procedure: Interpretative Phenomenological Analysis

The data analysis process of Interpretative Phenomenological Analysis (IPA) was conducted using the procedure suggested by Smith, Flowers and Larkin (2009).

Step 1

The researcher first transcribed all of the interviews. Next, the researcher read one participant's transcript three times before proceeding with any analysis. Both the process of transcribing and reading the transcript three times was a process that really helped the researcher to become familiar with the text. This helped not only to become familiar with the content but also, as Smith et al. (2009) suggests, become familiar with how a participant talks about and understands an issue. Whilst reading the transcript the researcher began to underline anything that was perceived to be interesting or important about what the participant talked about.

Step 2

The researcher engaged in making exploratory notes on the transcripts. These exploratory notes were categorised according to the suggestions by Smith et al. (2009): descriptive, linguistic and conceptual comments. Descriptive comments involve describing the content of what the participant is saying. Linguistic comments focus on the participant's use of language in relation to their perceptions. Conceptual comments are more interpretative and also known as 'questioning' hermeneutics. This is where researchers are asking critical questions of the text that go beyond what the participant is directly saying, yet, staying firmly grounded in participants' words. (Appendix XII gives an example of the exploratory note taking stage for 'Felix').

Step 3

Emergent themes were then generated. Both the exploratory notes and the interview transcript were used simultaneously. However, in line with Smith et al. (2009), the exploratory notes were used predominantly. The process of generating emergent themes involved looking for connections and/or patterns between the exploratory notes. Smith et al. (2009) describes this process as the 'hermeneutic circle', where you are oscillating between the specific part of the transcript/exploratory comment and thinking about it in the context of the whole. The purpose of generating emergent themes was to provide a statement about what appeared important for participants. Emergent themes were noted on the transcript (see Appendix XII for an example).

Step 4

The emergent themes were taken from the interview transcript and written in chronological order (example in Appendix XIII). The researcher then organised the emergent themes into clusters. The researcher attempted to make sense of the data by making connections between themes and grouping them together. To help with this element of the analysis the researcher used the processes highlighted by Smith et al. (2009) as a framework: abstraction, subsumption, function and numeration. Abstraction involves putting like with like and then thinking of a new name for the theme and subsumption is where a theme is used to become the superordinate theme. Numeration is thinking about the frequency with which a theme is supported and

function involves thinking about the meaning of the themes for the participant. Some themes were omitted when they did not appear to be relevant to any cluster or they did not enrich the data. In line with the idiographic focus of IPA, after superordinate themes and emergent themes were generated for each participant, the researcher completed stages 1-4 for each participant.

Step 5

This stage involved looking for patterns across the participants' superordinate and emergent themes. The researcher was able to see there were many similarities between participants' themes and accounts. Yet, some themes helped to illuminate aspects in other participants' themes and helped to develop a more nuanced understanding. This stage also involved the researcher sometimes creating new themes as another process of abstraction. This was supported by checking back to participants' transcripts to ensure that the researcher was remaining grounded in the actual accounts. After completion of this process the researcher produced a master table of superordinate and subordinate themes (Appendix XIV).

APPENDIX XII

Original interview transcript extract ('Felix'). Example of stage 2 and stage 3 of the interpretative phenomenological analysis process

Exploratory notes D-Descriptive, L- Linguistic, C-Conceptual comments	Interview transcript	Emergent themes
<p>Defining aggression as physical aggression directed towards other people (D). Perceptions of intentionality involved in aggression (D) Dissonance in perception of intentionality (D)</p> <p>Never – definitive (D). Changing perceptions - positive and negative perceptions about his brothers' aggression (D). Emotions underpin aggression or behaviour (C) Positive behaviour – showing work from school, engaging in conversation. (D) 'us' is brother on the out group? (C). Negative perception of aggression underpinned by the actual expression or presence of aggression (C)–even when it's at school (D). Belief of aggression to be inappropriate or unacceptable (C).</p> <p>Perception - unpredictability (D). Aggression is predictable re. expressed in both contexts (D).Unpredictability perception related to the speed at which aggression can start (D).Difficult to predict when the aggression will start (D).</p> <p>Hypervigilant at home (C) Prepared for aggression (D). Aggression is not constant (D). Continually and always aware (D). Negative perception attached to perceptions of unpredictability (C).</p> <p>Not immediately aware of coping efforts (D). Gaining a sense of control – underpinned by predicting and understanding more likely (C). Not verbal behaviour communicates likelihood of aggression expression (D).</p>	<p>(Rapport building and introduction to the interview in line with procedure in Appendix VIII).</p> <p>Can you tell me what the word aggression means to you? Um ... it means where someone <u>hits, pushes or kicks or punches</u>. It's like when someone <u>wants</u> to hurt someone else. Or they <u>maybe don't mean to</u> but they hurt them anyway.</p> <p>Everyone's experiences will be different. But what is it like for you living with [name of sibling with ASD]'s aggression? It's, it's <u>never the same</u>, it's <u>always changing between good and bad</u> because ... <u>sometimes</u> he'll be really <u>happy</u>. He'll come back from school and he'll <u>be wanting to explain everything he's done</u>, he'll be <u>really happy to show off his work and everything, that, um he thinks that will make us to feel happy about him</u>. But <u>then there will be days</u> where we'll come back and he's head butted a teacher or he's thrown a chair across the classroom.</p> <p>It sounds like it is a bit unpredictable then? <u>Yeah</u>. I mean he's aggressive in school and at home and sometimes he's not, but it's just really <u>changeable</u>, <u>like even in one place across a short period of time</u>. Like, he, well <u>you just don't know exactly</u> when he's going to be aggressive <u>because it can come on at any time</u>.</p> <p>Right, and how do you find that? <u>You're just on alert</u>, you feel like, I feel, I dunno <u>like you just have to be prepared</u>. I mean there are times when it is quieter but <u>I'm just always aware</u> that it can happen. It's <u>hard, you know, living like that</u>.</p> <p>Can you tell me about anything you feel that has helped you to deal with that? <u>Ummm, I guess</u>. I dunno. I mean I think ... I guess you <u>start to understand a bit when it's more likely</u>. <u>Just being around him</u>. I just sort of <u>learnt</u> what to, <u>look out for</u> when he may be about to get angry. I <u>can look at him</u> and from his, the <u>way he is standing</u> the way he is looking at something you can. If you just <u>see that same expression or body stance long enough</u> each time <u>before he gets angry</u> you kind of <u>clock</u> that well he could kick off, when he does a certain position.</p>	<p>Intentionality to harm. Dissonance in perception of intentionality.</p> <p>Unpredictability.</p> <p>Brother on the outgroup.</p> <p>Unpredictability-underpinned by speed of aggression.</p> <p>Hypervigilance in environment Need to feel prepared</p> <p>Gaining control Gaining understanding Observing non-verbal behaviour</p>

APPENDIX XIII

Chronological list of emergent themes for 'Felix'

Emergent theme
Intentionality to harm
Dissonance in perception of intentionality
Unpredictability
Brother on the out group
Unpredictability – underpinned by speed of aggression
Hyper vigilance in environment
Need to feel prepared
Gaining control
Ability to predict aggression
Respite when no aggression
Non-verbal behaviour communication
Gaining control through knowledge
Behaviour as communication
Unpredictability perceived as negative
On edge
Feeling alert
Mood influencing unpredictability
Rejection
Not being understood
Self as devalued
Targeted by brother
Youngest at bottom of family
Feel the pain
Sad, annoyed, bad – self devalued
Discrepancy between beliefs
Need to feel understood and empathy
Outsiders don't understand
Notices difficulties for others
Relates aggression to autism
Brother's lack of understanding
Gaining understanding through perceptions of lack of control
Reduced capacity to manage aggression
Parents as social support – managing aggression
Parents as social support -feeling understood
Social life as respite
Stress
Guilt
Aware of own limitations when dealing with aggression
Roles and responsibilities
Strategies to deal with aggression
Sense of empowerment
Gaining control – manipulation of environment
Acceptance as a process
Perceived controllability and acceptance
Personal growth
Social person
Respite needed

Distraction available
Process over time developing cognitions

APPENDIX XIV

Master table for group: superordinate and subordinate themes

Superordinate theme one: a threatened and disempowered self
Subordinate theme one: a sense of self as devalued
<p>Holly: “Well, when I was younger, I used to think, why me? I thought that it was just, he was doing it [the physical aggression] because he wanted to hurt me, I used to think</p> <p>Holly: “it upset me.”</p> <p>Stephen: “Like I thought that, like he doesn’t care he hurts me... like, he didn’t care I’m his brother”</p> <p>Felix: “He doesn’t really recognise that I’m trying to help, he recognises me as, as the one who can, he can let out his anger on I guess. It’s hard because, like, I’m, I’m there I’m trying to be the one who’s trying to help.”</p> <p>Felix: “rejected (long pause), by him, and a bit annoyed and sad”</p> <p>Joselyn: “It affects me [the aggression], it makes me feel bad, because you know, he’s my brother and like, he shouldn’t be doing that”</p> <p>Rebekah: “ I dunno, I guess it just felt like he didn’t respect me”</p>
Subordinate theme two: constructing aggression as unpredictable
<p>Felix: “you just don’t know exactly when he’s going to be aggression because it can come on at any time. You are just on alert, you feel like, I feel, I dunno like you just have to be prepared, but you can’t be. I mean there are times when it is quieter but I’m just always aware it can happen. It’s hard, you know, living like that”</p> <p>George: “I’ve just grown, kind of grown to live with the fact that his temper can just change pretty much instantly and he can be aggression”</p> <p>Rebekah: “you could be in the car, all fine, and then, something will happen, and the it will just start”</p> <p>Stephen: “you never really know when it’s gonna start. And it can happen anywhere, when we’re</p>

out and about, although, he does seem to be a bit better then. At home, like, he's so much worse, something will happen and it will all kick off it make me feel on edge around him, like, anxious like."

Superordinate theme two: gaining a sense of control

Subordinate theme one: actively searching to predict when

Stephen:

"if it's more predictable, you at least start to know the times when it's more likely"

Holly:

"I guess you just get it over time, like as I started to notice more about what seems to make it happen more, it helped me to feel like I know the times when it's more likely and, like.... It's not so random. Noise seems to be a thing for him, like fire alarms I kinda get, they're loud but can also be just cooker alarms or whatever."

George:

"you look, you learn, like, 'can I read my book', 'can I listen to Billy Bragg' and 'can I do my picture' because he says it over and over again, it's a clear sign of him getting agitated. I think we're more used to looking for the sign's now and to know when it is more likely to come and that's good"

Felix:

"I can look at him and from his, the way he is standing, the way he is looking at something you can. If you just see that same expression or body stance long enough each time before he gets angry you kind of clock that well he kick off, it makes it feel you can tell when it's going to happen, or well, when it could happen more. I mean there are plenty of times when it will just pop up but at least you can tell a bit when it's going to happen."

Subordinate theme two: developing strategies to manage the aggression

Holly:

"I suppose you learn, before I just used to get upset but I know, I've learnt what to do to calm him down. It is still hard him being aggressive, of course it is, but it just doesn't seem as much as a big deal as it used to. It makes me feel better because if we are on our own or in a shop or something, I feel like I can do something about it, I kind of know what helps to calm him down, I feel like I can deal with it"

Joselyn:

"When he starts to make certain noises I back off a bit, calm it down, stop what I'm.... pause be guided by him. You start to recognise over time what helps and what doesn't. You can't do it all the time, sometimes things don't work but it helps knowing that you can at least try to deal with it, like you can actually do something about it."

Rebekah:

"like I've watched my mum in the past. Like what she says to him, her tone, the words she says, the thing she gets him"

Stephen:

"I just sometimes feel like you don't know what to do, I want to know more, it feels like I just don't know how to manage it, what's best, what's not, what works or not. It's like I

don't have the ways to stop it"
Superordinate theme three: interpersonal coping
Subordinate theme one: relinquishing responsibility
<p>Rebekah: "unable to deal with it"</p> <p>Joselyn: "It sometimes gets way beyond anything I can manage and then I want my mum around so she can deal with it"</p> <p>George: "I wouldn't ever want to be on my own. That's so sad when you think about it actually... but it is, it's so important to me that either mum or dad is about so if [his bother with ASD] is really beginning to get out of control then....well if they weren't able to handle things at times I don't know what I would do"</p> <p>Holly: "but when it just gets too much, I leave it to my mam, or my brother"</p> <p>Holly: "yes because if I was on my own and he's Kicking and screaming and that, I could deal with it to a certain extent but then after a while I can't"</p>
Subordinate theme two: feeling understood
<p>Rebekah "It helps knowing that we're all in it together"</p> <p>Rebekah "That you feel like people understand how you feel and what it's like to live like, to know what it's like to deal with aggression a lot of the time"</p> <p>Felix: " I guess for me the worst thing I that no matter like people come up to you and say I feel bad for you, but they just won't really understand sort of what has happened, what it's really like"</p> <p>Holly: "My friends understand what I am going through, one of my friend's brother has autism so we talk about it ourselves to each other. She understands what we are going through and that feels good."</p>
Subordinate theme three: a sense of respite
<p>Felix: "I will try and see my friends on a day that my brother's being really aggressive, that way I can forget about it, and then in turn when I come back later he'll be fine and it was like he was never bad at all, like, like he was never being aggressive? That does help because then I spend my time having fun with my friends instead of getting stressed and getting annoyed at my brother"</p> <p>George: "Spending time with my friends feels like a breather"</p>

Rebekah:

"There are times where I'll just choose to get away. I suppose for me, I guess it feels like a bit of a sanctuary"

Superordinate theme four: making and changing meaning

Subordinate theme one: attributing aggression to their brother's reduced capacity

Holly:

"I used to get upset about why is he doing that to me? But as I got older I realised that it's because he's got autism. Because he's got autism he can't control his anger and if he doesn't like something and he gets frustrated he can't stop himself unless we calm him down"

Holly:

"it's been good because it's made me feel better, you know thinking that his aggression isn't me, it's him, because, he can't help it"

Joselyn:

"He's got a disability and he can't control it and I think, that, when I, I, started to understand that, that was good for me"

Joselyn:

"It just made it seem more understandable"

Joselyn:

"I remember asking my mum why, why is [brother with ASD] aggressive?"

Rebekah:

" I think his autism makes him see things very differently and he just can't control his anger"

George:

"he just can't control it at times like he hasn't learned to do that"

George:

"I can't remember exactly when it was but when I was a lot younger I remember my mum and dad sitting me down and explaining things, like, about his autism and stuff"

Stephen:

"it seems, it just seems strange. Here he doesn't care at all...he can control himself in school, in front of teachers. But in the house, he doesn't have a care in the world, it seems, so why should he do it here? It's like he doesn't care"

Subordinate theme two: accepting the way it is

Holly:

“it’s just how it is. You know, it’s there, part of what happens and you just have to deal with that...before it was, well, I did feel sad, but now, it’s just the way it is.”

Joselyn:

“I wish it would be different...I’ve learned it’s his condition and we have to live it, we can help him with it but it’s something we have to live with.”

Stephen:

“It gets me so frustrated. I...just want it to stop”

Felix:

“Over time, the long term things I’ve come to realise it’s one thing that you know you probably can’t change from him. And so you just have to live with it. You have to first understand it, then you have to, umm realise when it’s happening and then, umm, deal with it.”

Felix:

“Like you can’t completely change it and so you just have to get used to it. Like why keep wanting to change something you can’t completely change.”

Subordinate theme three: finding the silver lining

Felix:

“umm, sometimes I think about how it has made me a better person because...I know how to, be patient I know how to wait, I can listen. I can, it’s kind of improved me as a person, as sort of a social person because instead of being a bossy person I’m more of a laid back person. I don’t really like, sort of, being too loud sometimes. And so, I guess, I get that from [brother with ASD], from like his [brother with ASD]’s behaviour, because I can sort of think about what I do, what happens at home and I can put that into real life.”

Holly:

“I think it’s made me feel stronger, not in like all senses, but when you, because I’ve lived with him being aggressive for so long...it just makes me feel like I can handle more than maybe, like other people my age could.”

George:

“I think it’s made me understanding like...more understanding of how people feel when they’re living with something difficult in their life and that’s good.”